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Comprehensive Occupational Therapy in a Breast Cancer Program

Nicole Renee Scheiman
Nova Southeastern University

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Comprehensive Occupational Therapy in a Breast Cancer Program

Nicole R. Scheiman, MHS, OTR/L

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Capstone Mentor: Dr. Adrienne Lauer

Acknowledgments

The journey to complete my doctorate has resulted in a five-year-long dedicated commitment involving several very special individuals and organizations. I have continually been amazed at the body of knowledge I have gained throughout this process, which improves my clinical skills, my skills as a teaching professor, and my leadership skills within the profession of occupational therapy. I am thankful for this process, as I have grown as a person, clinician, professor, and leader. However, none of this would have been possible without the patience and giving of themselves and time from so many people.

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Abstract

The purpose of this capstone project is to develop an evidenced-based, innovative, and comprehensive occupational therapy evaluation and intervention protocol for breast cancer care. The contents of this paper will include an introduction into the current care provided to survivors, literature review on best practice in breast cancer care, outline of the procedures completed to discover what best practice care should be, results of these procedures, discussion of the results, and conclusion with proposed program and recommendations for further investigation. The concern investigated is the inconsistencies in care provided to survivors from the time of diagnosis throughout their lifespan or survivorship. A body of growing evidence supports the important need to address functional performance from the point of diagnosis through treatment and survivorship. A model of rehabilitation-based care has been put forward by the American Cancer Society as an optimal construct, however, there are significant inconsistencies in how this model is being leveraged to support breast cancer patients. These inconsistencies occur from cancer center to cancer center and even from physician to physician within the same cancer center. Participants in this capstone project include experts from the on-site residency, interviews with subject-matter experts and survivors as part of a focus group. The essential features of the methods used to discover best practice include a literature review, onsite residency, participation in an International Cancer Summit, continuing education, and completion of a focus group. Results indicate that additional services are needed in order to have an evidenced-based, innovative, and comprehensive occupational therapy breast cancer program. Conclusions provided aim to diminish inconsistencies in the current care being provided to this population.

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Comprehensive Occupational Therapy in a Breast Cancer Program

Chapter 1: Introduction

Cancer treatment inherently introduces medical interventions that negatively impact function. Recent efforts in the rehabilitation medicine community have called for improved integration of rehabilitation services into the cancer continuum of care. A framework for rehabilitation integration recognizes the importance of establishing a functional baseline assessment of an individual diagnosed with cancer. Assessing functional performance prior to medically directed cancer treatments allows us to better understand baseline function while alerting us to declines. Breast cancer treatment significantly impacts upper extremity and upper quadrant function impeding quality of life. Occupational therapy services have the potential to mitigate functional decline during and after cancer treatments. However, these services are not traditionally offered to cancer patients.

The lack of occupational therapy services in comprehensive breast cancer care results in little to no preventative and long-term services, which in turn, increases the risk of poor outcomes, e.g., decline in functional status and participation in occupation (M. Stubblefield, personal communication, November 11, 2016). The purpose of this capstone project is to develop an evidenced-based, innovative, and comprehensive occupational therapy evaluation and intervention protocol for inclusion in breast cancer care. The result will be an innovative breast cancer survivor intervention program with a more extensive focus on occupational therapy.

Background and Significance

Breast cancer is the second most common cancer in women in the US with a lifetime prevalence of nearly 12%, equating to about 1 in 8 U.S. women developing invasive breast cancer in their lifetime (Rundquist, Behrens, Happel, Kennedy, & Biggers, 2015). For women in the US, breast cancer death rates are second only to lung cancer (American Cancer Society, 2017).

From the time an individual is diagnosed with cancer through the rest of their lives, they are considered “survivors.” The most common definition for survivorship, and the definition used throughout this capstone project, is the time from initial cancer diagnosis through the remaining lifespan (Braveman & Hunter, 2017; Pearson & Twigg, 2013; National Cancer Institute, 2016). Accordingly, survivorship, also known as the cancer continuum, includes prevention, pre intervention, active intervention, maintenance, post intervention, palliative and end-of-life care (Braveman & Hunter, 2017). Currently, there are more than 2.8 million female survivors in the U.S., which includes women currently being treated and women who have completed their treatment regimen (American Cancer Society, 2017). Silver, Baima, and Mayer (2013) cautioned, however, that survival rates alone do not reflect the significant burden of cancer treatment. Treatments for breast cancer typically include surgery, radiation, or pharmaceuticals (chemotherapy and hormonal therapy) or any combination of these therapies (Peart, 2015). Treatments can cure cancer but can also result in potential secondary conditions or co-morbidities for the survivor, which can in turn, last throughout survivorship (Acebedo, 2015). Additionally, survivors who have undergone cancer treatments are at a life-long risk for comorbidities that include physical

impairments as well as recurrent disease (Stout, 2009). Co-morbidities include fatigue, muscular, and other physical impairments and psychological and cognitive impairments that contribute to a decline in health-related quality of life (Braveman & Hunter, 2017; Silver et al., 2013). Further, survivors are at risk for decreased occupational performance in activities of daily living and instrumental activities of daily living, as well as decreased participation in community, social, leisure, and work activities (Hunter, Gibson, Arbesman, & D'Amico, 2017; Silver et al., 2013; Polo and Smith, 2017). Many of these co-morbidities and occupational performance issues can be addressed within the scope of occupational therapy practice (Braveman & Hunter, 2017).

The Institute of Medicine and National Research Council have strongly suggested that cancer survivor research should include expanded exploration of alternative models of survivorship care, such as supportive care and rehabilitation programs (Institute of Medicine, 2013). However, in the U.S., cancer survivors typically do not receive specialized rehabilitation care for their cancer diagnosis (Hunter, Gibson, Arbesman, and D'Amico, 2017). Additionally, researchers found that only 32% of older adults with any type of cancer received occupational therapy within two years of diagnosis (Pergolotti, Cutchin, Weinberger, and Meyer, 2014). In comparison, rehabilitation is the standard of care for conditions including heart disease and cerebrovascular accidents (Cheville et al., & Segal et al., as cited in Hunter et al., 2017).

Survivors' unmet needs may result in various forms of disability. Physical disability is a leading cause of distress in the cancer population, despite scientific literature that has shown that rehabilitation improves pain, function, and quality of life in cancer survivors (Silver et al., 2013). Cheville, Troxel, Basford, and Kornblith (as cited

in Silver et al., 2013) found that in 163 women with metastatic breast cancer, 92% had at least one physical impairment, with a total of 530 impairments identified overall. Despite more than 90% of the participants needing cancer rehabilitation services (484 of these impairments (91%) required a physical rehabilitation intervention and 469 (88%) required physical and/or occupational therapy), fewer than 30% received this care. Treatment-related impairments continue to be present at checkpoints over a 6-year follow up period (Schmitz, Speck, Rye, DiSipio, and Hayes, 2012).

Kenyon, Mayer, & Owens (2014) completed a review of 137 articles studying the long-term or late effects (co-morbidities) of having breast cancer. The researchers determined that survivors of breast cancer faced challenges in the following areas:

- psychosocial, emotional, and cognitive well-being
- satisfaction with life
- sexuality
- body image
- anxiety
- fear of recurrence
- post-traumatic stress disorder
- depression
- cognitive dysfunction
- challenges to physical well-being
- adverse cardiovascular events
- fatigue
- lymphedema

- musculoskeletal symptoms
- accelerated bone loss and fractures
- pain and skin changes due to radiation
- disease recurrence
- and new breast cancers

In addition to these breast cancer-related co-morbidities, Stickle (2016) reported that breast cancer survivors experience lower self-confidence and self-esteem, along with the fear of physical limitations.

Dunne and Keenan (2016) reported on additional breast cancer-related co-morbidities, which include:

- axillary web syndrome
- post-mastectomy pain syndrome
- rotator cuff syndrome
- adhesive capsulitis
- arthralgia
- cervical radiculopathy
- brachial plexopathy
- cognitive impairments
- skin fibrosis and soft tissue adhesions
- and a decrease in occupational performance, and an overall decreased in quality of life

The above late effects are all amenable to rehabilitation services and with proactive assessment and intervention, occupational therapy services may help to reduce the

severity, mitigate impact on function and even prevent some of these impairments. The challenge is that doing so requires a different model of care delivery for occupational therapy services. It requires a proactive, prospective approach to screen for early identification of impairment and triage individuals for more intensive episodes of rehabilitation interventions when impairments are detected.

The challenge is to prevent, decrease, and contain the negative effects of having breast cancer that can limit survivors' participation in occupation and overall quality of life. Occupational therapy interventions range from addressing activities of daily living and instrumental activities of daily living via functional activity participation, energy conservation and work simplification, therapeutic exercise, adaptive equipment, neuromuscular re-education, manual therapy, and cognitive therapy (Pergolotti et al., 2016). Pergolotti et al., 2016, (Table 1) summarizes 11 research articles that outline various survivor needs, which can be addressed with occupational therapy services. Qualifying cancer-related comorbidities and the corresponding types of occupational therapy intervention that can address the co-morbidities are provided in Table 2 (Pergolotti et al., 2016).

Table 1

Summary of Relevant Research Evaluating the Needs for Occupational Therapy

Summary of relevant research evaluating the needs for occupational therapy

Authors	Patient population	Needs identified	Results
Cheville et al. [63]	Adults with metastatic breast cancer	Of 163 patients, 92% had at least 1 impairment, 88 required OT/PT, only 21% received treatment	Impairments are poorly addressed, even in centers with access to therapy
Cheville et al. [22]	Adults with cancer	Of 202 patients, 67% with functional problems, 1 in 5 reported a cognitive issue	No functional problems were addressed by therapy and only 1 patient received OT/PT
Cheville et al. [52]	Adults with stage IV breast cancer	The majority of 163 patients had 3 or more physical impairments	Disability occurs with a number of physical impairments and adverse symptoms accumulate slowly, making them more difficult to find and treat
Holm et al. [20]	Adults with cancer	Of 3,439 patients, one half reported sexual problems and one third reported a need for physical rehabilitation at 14 months after cancer diagnosis	Compared with women with breast cancer, those with colorectal, gynecological, and head and neck cancers reported more needs
Hansen et al. [64]	Adults with cancer	Of 3,439 patients, 60% had an unmet rehabilitation need, 40% had an unmet physical need	Perceived unmet need is related to decreased quality of life
Lehman et al. [65]	Adults with cancer	Of 805 patients, 35% had weakness, 30% had an ADL impairment, 25% had difficulty walking	Mental health issues were common and related to those with physical health issues
Movsas et al. [66]	Adults with cancer in acute care setting	Of 55 patients evaluated, 87% had rehabilitation needs, 76% had deconditioning, 58% had mobility impairment, 22% had ADL deficits	Of the 87% who had rehabilitation needs on admission, 9% received therapy
Pergolotti et al. [8]	Older adults with cancer in outpatient setting	Of 529 patients, 65% had an identified functional deficit (physical health, IADL, falls, cognition)	Only 9% received OT/PT in 1 year of identified deficit
Ross et al. [67]	Adults with cancer	Of 1,490 patients, 39% reported they were not offered needed physical rehabilitation	Younger patients and those who are divorced or single were more likely to have difficulty returning to everyday life
Söderback et al. [68]	Adults with cancer	Of 102 patients, 56% reported a perceived need for OT; only 7 were referred	Once oncologists were aware of OT, they stated that 59% of the patients would need a referral
Veloso et al. [69]	Adults with cancer	Of 4,346 patients, 19% needed physical rehabilitation, 17% needed practical help, 14% needed information on how to return to work	Young age, male sex, low educational level, and living alone increased risk for unmet needs
Abbreviations: ADL, activity of daily living; IADL, instrumental activity of daily living; OT, occupational therapy; PT, physical therapy.			

Table 2

Qualifying Conditions and Potential Interventions for Occupational Therapy.

Qualifying conditions and potential interventions for occupational therapy

Qualifying conditions	Types of interventions provided by an occupational therapist
ADL/IADL limitation	ADL/IADL self-care, functional activity participation, therapeutic exercise, durable medical equipment recommendations
Debility, fatigue, poor endurance	Therapeutic exercise, ADL/IADL self-care, functional activity participation, durable medical equipment recommendations, energy conservation
Neuropathy	Neuromuscular re-education, ADL/IADL self-care, therapeutic activity, therapeutic exercise, manual therapy, durable medical equipment recommendations
Lymphedema	Manual therapy, ADL/IADL self-care, functional activity participation
Cognitive decline	Cognitive therapy, ADL/IADL self-care, functional activity participation
Upper extremity impairment	ADL/IADL self-care management, neuromuscular re-education, functional activity participation, therapeutic exercise, manual therapy
Balance	ADL/IADL self-care management, neuromuscular re-education, functional activity participation, therapeutic exercise, durable medical equipment recommendations
Pain	Functional activity participation, ADL/IADL self-care management, therapeutic exercise, durable medical equipment recommendations

Abbreviations: ADL, activity of daily living; IADL, instrumental activity of daily living.

Purpose and Objectives

The lack of consistent rehabilitation care that is provided throughout the cancer continuum paired with potentially preventable functional co-morbidities prompted the pursuit of this capstone project. The goal is to develop an evidence-based, innovative, occupational therapy breast cancer program grounded in the Empowerment Model, Peri-Operative Home Model, and the Person-Environment-Occupation-Performance Model and supported by adult learning theory and use of the teach-back method, and based on the Prospective Surveillance Model for breast cancer patients (American Cancer Society, 2012). Providing a comprehensive occupational therapy program offers the potential to prevent or limit secondary complications and can result in decreased economic burden both for the survivor and overall health care costs as demonstrated in table 3 (Stout et al., 2012).

Table 3

Economic Burden

Intervention Protocols With Cost Outline for Skilled Therapy and Durable Medical Equipment Costs With a 1-Year Timeline

Services and Supplies	Prospective Surveillance Model	Cost	Traditional Model	Cost
Skilled therapy	<ul style="list-style-type: none"> All patients are seen for baseline (preoperative) and 1-, 3-, 6-, 9-, and 12-month postsurgery visits (6 visits) Initial visit: coded as an evaluation (97001–1 visit) Follow-up: coded as re-evaluation (97002–5 visits) Prospective surveillance model cost If lymphedema is diagnosed: <ul style="list-style-type: none"> If greater than 3%–5% volume increase, a ready-made sleeve and gauntlet are issued for daily wear for 4 weeks Patient returns in 4 weeks for follow-up (97002–1 visit) If volume is reduced, continue surveillance schedule Continue modified garment use Replace garments in 6–9 months If volume is not reduced, initiate decongestive therapy 	\$69.29 \$185.75 \$255.04 \$37.15	If lymphedema is diagnosed: <ul style="list-style-type: none"> Patient is referred by the medical provider for therapy Initial visit: coded as an evaluation (97001–1 visit) Decongestive therapy: 5 visits/week for 2 weeks then 3 visits/week for 1 week^a Each visit is 1 hour in duration and requires one-to-one care (4 units of 97140 each visit for 13 visits) At the completion of therapy, patient receives custom-made compression garments (sleeve and gauntlet) One additional visit is undertaken 6 months later for renewal of garments (97002–1 visit) 	\$69.29 \$1,388.48 \$37.15
Compression bandage supplies	None required	\$0	2 sets of bandages	\$230.00
Compression garment supplies	4 ready-made arm sleeves 4 ready-made hand gauntlets	\$344.00	4 custom-made arm sleeves 4 custom-made hand gloves	\$1,400.00
Prospective surveillance model cost		\$636.19	Traditional model cost	\$3,124.92

^a Average length of therapy frequency and duration.

Shih et al., (2009) concluded that the economic burden of breast cancer-related lymphedema is an additional \$7440 to \$11,585 per year per survivor. Therefore, for ten survivors with lymphedema, the additional annual health care costs to treat lymphedema ranges from \$74,400 to \$115,850. Additionally, cancer survivors become life-long users of health care, as cancer is a chronic condition, therefore continuing to increase survivors' and society's health care costs (J. Rowland, personal communication, November 11, 2016). This information supports Thakur, Bhat, & Kaur (2016) and Stout et al., (2012) recommendations for proactive functional screening and early rehabilitation intervention paired with education to prevent the costly comorbidities.

Capstone Project Objectives

1. Identify the components of a comprehensive occupational therapy breast cancer care program.
2. Develop a comprehensive occupational therapy evaluation and intervention protocol.
3. Develop program evaluations to measure both program and survivor-outcomes.

Definition of Terms

1. Axillary lymph node dissection. Axillary lymph node dissection is a surgical procedure involving removal of some or all of the lymph nodes in the underarm area (axilla) for the purpose of diagnosing and staging breast cancer (Zuther, Norton, & Armer, 2013).
2. Breast cancer-related lymphedema. Lymphedema associated with onset as a result of treatment for breast cancer, including axillary lymph node dissection, radiation, and chemotherapy (Hsiao, Hong, Chou, & Lu, 2015).
4. Breast cancer survivor. Typically refers to anyone diagnosed with breast cancer who is still living (Zuther et al., 2013).
5. Cellulitis. Cellulitis is a spreading bacterial infection just below the skin surface. It is most commonly caused by *Streptococcus pyrogens* or *Staphylococcus aureus* ("Cellulitis," n.d.).
6. Chemo brain. A colloquial term for difficulties with concentration and memory that may follow the administration of some forms of cancer chemotherapy ("Chemo brain," n.d.).

7. Complete decongestive therapy. Complete decongestive therapy is a lymphedema treatment program with the following cornerstones of treatment: manual lymphatic drainage, multi-layer compression bandaging, skin care, self-care training and exercise (Hsiao, Liu, Lin, Chou, & Lu, 2015).
8. Dyspareunia. Difficult or painful sexual intercourse (“Dyspareunia,” n.d.)
9. Lymphedema. The abnormal accumulation of protein-rich fluids in the bodies’ interstitial spaces (Ferguson, Swaroop, Horick, Skolny, Miller, Jammalo, & Brunell, 2016; Lu, Hong, Chou, & Hsiao, 2015).
10. Manual lymphatic drainage. Manual lymphatic drainage is a manual technique completed on a patient by a skilled practitioner, which is designed to improve lymphatic flow and decrease lymphedema (Hsiao et al., 2015).
11. Occupation. Any task, which occupies an individual’s time. For example, everyday tasks, such as dressing, working, walking the dog, and so forth (American Occupational Therapy Association, 2014).

Chapter 2: Literature Review

Chapter 2 reviews the literature in order to define what an evidenced-based, innovative, and comprehensive breast cancer rehabilitation program entails. This review includes an in-depth review of occupational therapy and breast cancer care, in addition to reviewing literature on theories and models as a foundation for the program. Literature from 1981 to 2017 was reviewed. Search terms include breast cancer, breast cancer-related lymphedema, lymphoedema, and comprehensive breast cancer care, rehabilitation for breast cancer, occupational therapy, occupational therapy and breast cancer, and breast cancer survivorship. Literature was not limited by geography. However, all literature was limited to print in English. The literature review focused on the potentially preventable co-morbidities that can and often do arise because of breast cancer treatments, particularly breast cancer-related lymphedema, as it is a chronic, non-curable comorbidity that can significantly decrease a survivors' quality of life.

Overview of Current and Best Practice

To design a comprehensive breast cancer rehabilitation program, it is important to learn what is currently known about comprehensive breast cancer care and how researchers, experts in the field, and survivors define and describe the best care. In an attempt to create an evidenced-based program, five of the top ten cancer centers in the US according to Mulcahy (2016), were reviewed by the capstone author.

The centers reviewed include:

- Memorial Sloan-Kettering in New York City
- University of Texas M.D. Anderson in Houston
- Mayo Clinic in Rochester

- Dana-Farber/Brigham and Women's Cancer Center in Boston
- Johns Hopkins Hospital in Baltimore

These top five cancer centers were studied for their provision of holistic, patient-centered care, from the onset of cancer through the survivors' lifespan or survivorship. All five-breast cancer centers are considered large entities, having over 400 beds. Often within a larger cancer center, there are more physicians and support services/personnel to coordinate care (Begley, 2009). In Begley's opinion, having more physician and support personnel can result in survivors not only receiving cancer care sooner but also typically receiving more services, which can include education on prevention of potential co-morbidities, ultimately increasing the survivors' quality of life (Begley, 2009).

The M.D. Anderson model functions as a large central center working with various smaller centers. As a large cancer center, M.D. Anderson has the ability to provide more physician and staff/personnel. M.D. Anderson's breast-cancer department alone has 24 medical oncologists, 13 surgeons, seven radiation oncologists, 16 radiologists, and 13 pathologists (Begley, 2009). Every medical oncologist meets with all the other oncologists to discuss every cancer case. Therefore, the patient receives 23 second opinions (Begley, 2009). To assist smaller community hospitals with providing similar care, M.D. Anderson is forming partnerships with community hospitals to share their expertise (Begley, 2009), demonstrating acknowledgment and understanding of the need for improved comprehensive care services, particularly at smaller community hospitals.

Memorial Sloan-Kettering in New York City presented with the most comprehensive program providing a wide array of ancillary services including:

- rehabilitation and exercise
- palliative care and pain management
- counseling and support
- specialized programming for older adults
- an integrative medicine department that includes massage, acupuncture
- hypnotherapy, meditation, visualization, music therapy, and nutrition counseling
- dermatology and skincare
- sexual health
- fertility services
- tobacco treatment
- virtual library with a dedicated Web specialist
- clinical trials
- an entire department dedicated to patient and caregiver education

Memorial Sloan-Kettering prides themselves on providing survivors with early intervention paired with an individualized patient approach. Six physiatrists guide the comprehensive rehabilitation services department along with a large department of occupational and physical therapy practitioners with specialty certifications to treat specific cancer needs such as lymphedema. Listed specifically on Memorial Sloan-Kettering's Web site includes occupational therapy services for treatment of the following conditions: upper extremity pain; loss of arm strength; loss of arm range of motion; memory loss; decreased concentration; difficulty with dressing, grooming, or bathing; energy conservation; and core balance.

The Mayo Clinic-Rochester's Stephen and Barbara Slaggie Family Cancer Education Center houses one of the largest cancer resource collection in the nation. The education center assists over 35,000 visitors a year. Services offered include:

- brochures, books, videos, magazines and scientific journals
- Mayo Clinic Cancer Center and Cancer Education Program publications
- syndicated video health information from Mayo Clinic
- computer resources, including Internet access with recommended reputable websites
- librarian-mediated medical literature searches
- medical reference books
- Spanish-language materials

Of the centers studied, Mayo Clinic-Rochester appears to have the most comprehensive educational center based on being one of the largest cancer resources in the nation. The Mayo Clinic-Rochester and Dana Farber Brigham and Women's Cancer Center were the only centers to provide a return to work program. The Dana Farber Brigham and Women's Cancer Center return to work program is housed in their Occupational Medicine Program. The program focuses on functional limitations, risk factors that may delay recovery, early contact with the employer for potential work accommodations, and willingness of the patient to return to work. There is also an extensive team of professionals including:

- pain management physician
- occupational medicine specialist
- nursing

- occupational and physical therapists
- psychologist
- case manager
- pharmacist
- volunteer director

Johns Hopkins offers a comprehensive breast cancer survivorship program that exists to address survivors' individual needs and can involve:

- developing an individualized survivorship or transition care plan
- determining other evaluations or referrals, including genetic risk assessment or reconstructive surgery that may be needed
- identifying and assisting with management of current or potential late side effects of treatment
- discussing coordination of medical care and possible follow up care such as psychosocial support, bone health, cancer rehabilitation, sexual health, fertility or nutrition
- providing educational support, including helpful information on topics such as reducing the risk of recurrence and embracing survivorship as a family
- providing access to online education through blogs, videos, and social media
- providing access to informational webinars that many times include live Q&A session
- sharing new research being conducted at the Johns Hopkins Kimmel Cancer Center
- offering suggestions and referrals for wellness activities

- providing support group information to assist in the transition of care

See Table 3 for a comparison of the services provided by the top five cancer centers and Parkview Regional Medical Center (associated with this capstone project).

Table 3

Comparison of the Top Five Cancer Centers and Parkview Regional Medical Center

Cancer Service Provided	Memorial Sloan-Kettering-New York City	University of Texas M.D. Anderson-Houston	Mayo Clinic-Rochester	Dana-Farber Brigham and Women Cancer Center-Boston	Johns Hopkins Hospital-Baltimore	Parkview Regional Medical Center
Animal Assisted Therapy	X	X	X		X	
Lymphedema Program	X**	X**		X**	X**	
Bio Impedance Spectroscopy	X**	X**				
Body Image Counseling	X	X				
Bone/Musculoskeletal Health Center	X**	X**	X**		X**	
Bra/Prosthetics	X	X	X			
Mobile Patient Application	X	X				
Caring for the Caregiver Program	X	X		X	X	
Cosmetology/Wig Boutique						
Donation	X	X	X		X	X
Daycare						
Distress						
Depression						
Anxiety	X	X	X	X	X	X
Exercise Physiologist	X	X				
Fatigue/Sleep Clinic	X	X			X	(continued)

Cancer Service Provided	Memorial Sloan-Kettering-New York City	University of Texas M.D. Anderson-Houston	Mayo Clinic-Rochester	Dana-Farber Brigham and Women Cancer Center-Boston	Johns Hopkins Hospital-Baltimore	Parkview Regional Medical Center
Financial & Genetics Counseling	X	X	X	X	X	X
Gift Shop -Breast Cancer Specific						
Garden		X		X	X	
Metabolic Testing						
Weight Management						
Nutrition Services						
Cooking Class	X	X	X	X	X	X
Pain Management Palliative Care/CAM	X	X	X	X	X	X
Psychological Spiritual						
Cognitive	X	X	X	X	X	
Recreational and Music Therapy/Art Writing	X	X	X			
Return to Work			X	X		
Smoking Cessation	X	X	X			
Support Groups Including Web-Based	X					
Survivor Resource Library	X	X	X	X	X	(continued)
Survivor Volunteer Program	X	X	X			
Tattoo Artist						
Yoga and Pilate's	X	X		X	X	

Note: *Based on review of Web site offerings on 01/12/2017 ** Occupational Therapy included in the provision of this service.

The evidence is clear that there are inconsistencies even between the five best cancer centers. All five top centers and the community hospital provide financial services, genetics counseling, nutrition services, pain management, psychological services, sexual health, and a survivor-dedicated library. Currently, Memorial Sloan Kettering provides the most comprehensive breast cancer care services based on the number of services provided overall. The services provided by the top five centers provide supportive care for survivors, but are significantly lacking the attention to the survivors' functional needs and the rehabilitation focus on prevention of potential functional limitations secondary to breast cancer-related comorbidities. This gap in services is striking and important to the overall quality of life for the survivors. Occupational therapy services can reduce this gap by providing services aligned with comprehensive cancer care.

Supporting Theory and Models

There are many theories that explain human behavior, development, and learning. These human and health-related theories are tools that assist practitioners to gather and organize information to provide positive contributions to healthcare (Christiansen, Baum, & Bass, (2015). Theories provide knowledge that guides our understanding of concepts or constructs that explain the human behavior (Christiansen et al., 2015). Theories are the highest order of knowledge and have been tested with their principles accepted (Christiansen et al., 2015). In order to create an innovative and comprehensive occupational therapy breast cancer program, theories and models must be studied to determine which best guide the development and success of the program. Occupational therapy theories and models are used to guide occupational therapy practice to positively

influence patient or client outcomes and support the practitioner and the client working toward the client's goals.

Adult Learning Theory

The Adult Learning Theory focuses on the transfer of knowledge and suggests that learning for adults is not automatic and must be enabled (Malick, Das, & Khan, 2008). The adult learner is self-directing (prefers autonomy) and begins the learning process with an increased amount of life experience (Breese & French, 2012; McNeil, Hughes, Toohey, & Dowton, 2006; Merriam, 2001). An adult's experiences become the source of their self-identity, thus using their experience as part of learning, is highly beneficial (Breese & French, 2012; Green & Ellis, 1997; McNeil, Hughes, Toohey, & Dowton, 2006; M. Puliyl, J. Puliyl, & U. Puliyl, 1999). Adults are ready to learn when there is a clear, meaningful, and perceived need to learn and adults benefit most from an atmosphere of collaboration and mutual respect with the educational provider (Breese & French, 2012; Green & Ellis, 1997; McNeil, Hughes, Toohey, & Dowton, 2006; M. Puliyl, J. Puliyl, & U. Puliyl, 1999). Adult learners favor having responsibility for their decisions and desire to be viewed as capable of self-direction (Green & Ellis, 1997; M. Puliyl, J. Puliyl, & U. Puliyl, 1999). Lastly, adult learners are life or task-centered and prove responsive to some external motivators, but their strongest motivation for learning comes internally (Green & Ellis, 1997; Merriam, 2001).

The Adult Learning Theory will be leveraged in the proposed program starting during the pre-operative visit as the therapist gathers the occupational profile data. This process will include creating an atmosphere of cooperation as the therapist uses their skills in the therapeutic use of self, discovering the survivor's previous experiences, and

providing the survivor with information on the benefits of participating in the program in order to enhance functional recovery. This process will continue throughout the post-operative session and outpatient therapy session/s as well.

Empowerment Model

The Empowerment Model is the structure and application of processes that enhance participation and control over life situations for goal achievement (Fisher & Howell, 2010). The Empowerment Model was studied by the primary investigator for its relevance and applicability to assist survivors to increase participation and control over their new life situation of having cancer and working towards goals to prevent or improve co-morbidities.

The term empowerment first came into common use concerning civil rights in 1975 (Lausch, 2011). Empowerment entails supporting individuals and giving them opportunities to take control of themselves; it involves giving control and giving a choice (Christiansen et al., 2015). For researchers and health care practitioners, empowerment represents a strengths-based, non-expert driven approach that focuses on the ability of the individual facing difficult life circumstances to define and actively engage in solutions to the problems (Peterson, 2014). Additionally, the Empowerment Model focuses on enhancing an individual's sense of personal identity and self-worth and on the development of life skills, including decision-making and problem-solving skills, so that the individual will be willing and able to take control of their own life. People are encouraged to engage in critical thinking and critical action at an individual level (Peterson, 2014).

One example is psychological empowerment, which is the provision of knowledge, skills, and resources to increase control over an individual's social and environmental factors in their life (Fisher & Howell, 2010). Additionally, patient or client-centered care has its basis in empowerment (Fisher & Howell, 2010).

The five main elements of patient empowerment include Groen et al., (2015):

- being autonomous and respected
- having knowledge
- having psychosocial and behavioral skills
- perceiving support from community, family, and friends
- perceiving oneself to be useful

The last two elements were specifically identified with cancer survivors. These elements can be used to guide approaches to providing survivor education from the pre-operative phase throughout survivorship. Farbia, Masoud, Marzeyeh, & Alireza, (2014) completed a study and found information as one of the main empowerment needs for survivors, which corresponds to Groen et al., (2015) study.

Kane, Jasperse, Boland, Herst, (2014) studied 15 cancer survivors through dialogical interviewing over three months. Five themes of dialogical interviewing to enhance the empowerment process included:

- building rapport
- assessing disempowerment issues
- facilitating critical thinking
- joint creation
- resource connecting and positive feedback

The Empowerment Model will be utilized when designing interventions that will guide the proposed project to ensure survivors have a program that assists them to improve participation and control over their new life context of being a survivor.

Consistent with the Empowerment Model, the program is designed to:

- increase survivors' participation (e.g., in occupation)
- increase a person's control over their life circumstances and regain physical and cognitive/social control
- be goal oriented (e.g., give an example of a goal that a survivor in the program might set)
- provide knowledge on occupation, prevention, and treatment of current situation and opportunities that result from increased knowledge and independence

The Empowerment Model supports addressing personal identity: having a body part removed, e.g., a mastectomy can significantly effect one's identity and if not dealt with appropriately can lead to setbacks in the therapeutic process.

Perioperative Surgical Home Model

Many medical specialties are creating new models of practice because of the creation of the Triple Aim Initiative by the Institute for Healthcare Improvement (Gentile, 2017). The Triple Aim Initiative's goals are to provide improved quality of care, increased patient satisfaction, and cost containment (Berwick, Nolan, & Whittington, 2008). One model created to work towards this initiative is the Perioperative Surgical Home Model introduced by the American Society of Anesthesiologists (American Society of Anesthesiologists, 2014).

The Perioperative Surgical Home Model is modeled after the Medical Home Model and is a patient-centered, physician-led, interdisciplinary team-based model that coordinates care from pre-procedure assessment through the acute care episode, recovery, and post-acute care (American Society of Anesthesiologists, 2014; Gentile, 2017). This seamless care is also evidenced-based and focuses on decreasing variability of care provided (Patterson & Soto, 2014). Additionally, this model was created to address the fragmented and disconnected care that is often paired with the individuals' anxiety of having to have a surgical procedure. This scenario of fragmented care and anxiety can contribute to decreased patient satisfaction and poor outcomes (Warner, 2012).

Patterson and Soto (2014) believed that the healthcare areas getting most attention via the Perioperative Surgical Home Model have been in the areas of medications, techniques, and devices that can decrease variability in health services. They believed that the most important aspect is often ignored and that aspect is patient education and empowerment. The same researchers reviewed the literature regarding preoperative education for individuals with cancer and summarized that face-to-face education provided more improvement on anxiety, satisfaction, knowledge, and health care costs, whereas audio-visual and multimedia interventions only improved satisfaction and knowledge, and written interventions had mixed results. A perioperative surgical home model brings together a patient-centered, physician-led, interdisciplinary team for providing better care (Gentile, 2017).

The Perioperative Surgical Home Model was chosen to design the flow of the program because it supports the importance of comprehensive care from diagnosis throughout survivorship. This model starts at diagnosis, works through acute care, then

outpatient, and then long-term surveillance. This is supported by evidence for preoperative assessment and prehabilitation in the cancer population (Carli et al, 2017). A shared care model such as this is also supported by a recent National Institutes of Health initiative in cancer rehabilitation. This initiative recommended greater shared decision making and greater integration of rehabilitation services into the cancer continuum (Stout, 2016). Additionally, the model is patient centered; physician led as they initiate occupational therapy services, and the program mirrors the perioperative home model because it coordinates care from pre-procedure assessment, through acute care episodes, and continues through recovery and post-acute care. New models for cancer rehabilitation are needed and their value is being recognized and promoted in the literature. Recently, Cheville et al., (2017) reported on the various cancer rehab models and provided strong evidence to support greater integration of rehabilitation services into the cancer care continuum.

Person-Environment-Occupation-Performance Model

Models are used in occupational therapy to provide clarity in the profession's assumptions about humans and occupation, and to provide a guide for professional and clinical reasoning (Owen, Adams, & Franszen, 2014). Models also assist with defining the profession's scope of practice by giving practitioners a focus for intervention and its domain of concern (Owen, Adams, & Franszen, 2014). Additionally, models improve professionalism and accountability by providing a means for ethical decision making and assist the practitioner with collecting information in a systematic and organized fashion, guiding intervention and providing solutions (Owen, Adams, & Franszen, 2014).

The Person-Environment-Occupation-Performance Model was created in 1985 and published in 1991 by Charles Christiansen and Carolyn Baum and updated in 1997 (Christiansen et al., 2015). The theoretical base of the Person-Environment-Occupation-Performance Model uses assumptions including the following:

- people have an innate drive to explore their environment and demonstrate mastery within it
- people confront challenges of daily living through adaptation and use of their resources to master demands
- people derive a sense of self-fulfillment from mastery and a sense of self-identity from meaningful participation in occupations
- occupational performance is influenced by many factors including person, unique environment, occupations that consist of one's actions and tasks and ultimately create one's life roles
- the Person-Environment-Occupation-Performance Model represents a transactional relationship that is interdependent among its parts
- occupational performance describes the actions that are meaningful to the individual as he or she self-manages, care for others, works, plays, and participates fully in home and community life (Christiansen, et al., 2015)

The Person-Environment-Occupation-Performance Model centers around three central themes of person, environment, and occupation. The fourth aspect, performance, is considered the outcome of the transaction between persons, their environments, and their occupations (Christiansen, et al., 2015).

There are four major components of the Person-Environment-Occupation-Performance model:

- occupations (what people need or want to do in their daily lives)
 - performance (actual act of doing the occupation)
 - person (composed of physiological, psychological, neurobehavioral, cognitive, and spiritual factors that are intrinsic in nature)
 - environment (composed or built of physical, natural, cultural, societal, and social interactive factors and social and economic systems that are extrinsic in nature)
- (Christiansen, et al., 2015)

The Person-Environment-Occupation-Performance Model uses a client-centered practice approach that applies to individuals, organizations, and populations.

Additionally, it can be applied to health promotion programs both in the community and in a rehabilitation setting (Christiansen, et al., 2015). The Person-Environment-Occupation-Performance Model has been created through extensive research that demonstrates the relevance of how an individual's behaviors and their environment are interconnected in a significant way (Christiansen, et al., 2015). This model concentrates on an individual's necessary and meaningful daily occupations that may be restricted due to health conditions or disability and focuses on the intrinsic and extrinsic factors, which could have led to the health condition or disability. Additionally, the Person-Environment-Occupation-Performance Model complements global health care views as it stresses the importance of health and well-being (Christiansen, et al., 2015).

Occupational therapy practitioners work with clients is to develop a plan of care with interventions designed to assist them to regain occupational performance (Cole &

Tufano, 2008). Christiansen and Baum (1997) provided five major schemes for improving performance:

- modification of physical environments
- application of technical aids and devices
- strategies for sensory and neuromotor remediation
- occupation as a therapeutic means
- teaching and learning strategies

These themes will be used in the proposed project to improve survivors' occupational performance with functional activities and to improve overall quality of life. The Person-Environment-Occupation-Performance Model has been chosen as the primary model for this project because it is client-centered and focuses on the internal and external factors of the survivor and provides occupational therapy practitioners with an understanding of the survivor and their unique needs. This model assists the occupational therapy practitioner to identify the survivors' resources and barriers to achieving occupational performance (Wong & Fisher, 2015).

The Person-Environment-Occupation-Performance Model goes beyond providing treatment in an attempt to "fix" the survivor and suggests that without actually knowing what the survivors' environmental factors consist of, they may go back to their environment to fail. For example, a survivor can receive occupational therapy for upper extremity lymphedema that decreases swelling, but if the treatment does not include learning about the survivor's environment such as her job, the therapy may not be successful. If, for example, this survivor works as a florist and is exposed to constant punctures from thorns and dirt etc., the survivor could risk furthering her lymphedema

status and increase her risk of a cellulitic infection. Teaching the survivor about the relationship between her condition and her environment would provide her with adaptive ways to prevent these additional problems, such as using gloves, different tools, and proper body mechanics. Additional environmental factors to be assessed could include support the survivors receive or lack of support from the healthcare teams, from their caregivers, and support groups (Wong & Fisher, 2015).

Additionally, the Person-Environment-Occupation-Performance model provides a means to connect the relationship between the survivor and their desired occupations through customized evaluation and treatment sessions focused on the survivor goals. The occupational therapy practitioner is able to take the information gathered and address both the intrinsic and extrinsic factors limiting performance (Wong & Fisher, 2015).

The HOPE Diagram (Figure 1) shows the relationship between the theories and models used in the program. The program will include preventative and rehabilitative interventional components to promote optimal function during and after cancer treatment. This will involve ongoing and repeated interval interactions with the survivor in a proactive manner to reassess, educate and promote optimal function.

Educational interventions will be introduced and implemented leveraging the Adult Learning Theory and use of the Teach-Back Method in order to enhance carryover, recall, and help to promote adherence. When cancer survivors are diagnosed there is a significant amount of information they receive, therefore it is critical to implement approaches to education that are based on theories that can help with uptake, retention and understanding.

Cancer diagnosis is a tenuous time during which patients are faced with making a number of decisions about their care. Leveraging concepts from the empowerment model will enable and promote patients to be active in shared decision making about their care and recovery. During the pre-operative visit and completion of the occupational profile, survivor's participation will be key as they work with the therapist to establish goals and a plan of care they desire. This active participation that is goal-oriented will provide the survivor a sense of control over their current life events and encourage more active physical, cognitive and social control.

The occupational therapy program components for screening, assessment and intervention will leverage the Peri-Operative Surgical Home Model, which provides for the structured pre-determined visits for all survivors. Having a structured program designed from the Peri-Operative Surgical Home model provides for improved and consistent quality of care for all survivors, increased satisfaction as their needs for information and control are addressed, and cost-containment via the prevention of long-term chronic comorbidities.

Throughout these predetermined therapeutic intervals, the evaluations and treatments are designed around and incorporate the Person-Environment-Occupation-Performance model. This foundational occupational therapy model ensures that the core of occupational therapy treatment, occupation, is the therapeutic driver for interventional techniques. Examples of potential therapeutic interventions using the five major schemes of the Person-Environment-Occupation-Performance Model (Christiansen and Baum, 1997) could include the modifications of the survivor's home environment using a bath tub bench due to increased fatigue during showering requiring the survivor to sit for

increased safety. Work environments may need to be modified to allow for safe use of the surgical-side upper extremity so as to avoid overuse and the potential risk of lymphedema. Application of devices could include the use of a bra dressing aid, a seat belt cushion to prevent irritation of the surgical side during driving, and the use of pillows for positioning of the surgical side arm during sleep to improve sleep performance and increased comfort.

It is anticipated that every patient diagnosed with breast cancer will receive a baseline functional assessment and educational interventions, every patient will be followed on an interval basis for reassessment and reinforcement of core concepts around maintaining function. If, upon reassessment, meaningful change in functional decline over time is noted, the patient will be referred for more intensive occupational therapy services to restore function and prevent further deficits.

Figure 1

HOPE Diagram (Human, Occupation, Performance, Environment)



Overview-Occupational Therapy and Breast Cancer

Cancer rehabilitation can benefit survivors with cancer from diagnosis to end-of-life care focusing on symptoms management, return to work, or community participation just to name a few areas (Gamble et al., as cited in Hunter, 2017). Braveman and Hunter (2017) summarize what is considered strong evidence, in a review of 138 studies on cancer and rehabilitation.

Strong evidence:

- supports the effectiveness of multidisciplinary rehabilitation programs in cancer rehabilitation, showing effectiveness with different cancers, at different stages of the disease, and for cancer survivors of various ages
- supports the benefits of exercise in reducing fatigue and improving quality of life. This benefit extends to exercise programs for people after radiation therapy or chemotherapy
- reveals benefits from nonpharmacological interventions, including problem solving, energy conservation, and education, for improving breathlessness
- supports using psychosocial strategies to reduce anxiety and depression compared with routine care, but the effects were not sustained long term after therapy ended. Cognitive-behavioral and educational interventions, as well as mindfulness-based therapy, were found to decrease anxiety and depression in the short term
- supports exercise as safe and feasible for patients with most types and stages of cancer and at varying ages

- supports exercise for women with breast cancer to improve quality of life and for aerobic exercise to reduce fatigue
- supports exercise as a means of increasing muscle tone, strength, and lung capacity, without causing lymphedema or exacerbating it in patients who already had it
- supports exercise providing physiological and psychological benefits for cancer survivors during rehabilitation
- supports using compression bandages, worn daily, to control lymphedema volume. Manual lymph drainage did not improve results when performed in additions to the wearing of a compression sleeve
- strong evidence supports exercise to improve range of motion, quality of life, mood, and weight loss without increasing lymphedema symptoms
- evidence supports physical training (strength, interval, and home-based activity) in place of usual care to promote interest in sex and sexual activity among male prostate cancer survivors

A critically appraised study of 20 articles indicated that multidisciplinary rehabilitation programs (specific disciplines where not provided) are beneficial for cancer survivors, regardless of cancer type or stage of cancer (Hunter et al., 2016). This review contained two systematic reviews, 12 level I randomized control trials, and 4 with level II, 1 with level III and 1 with level IV evidence. Thakur et al., (2016) completed a randomized control trial on 20 subjects divided into two groups. Group A received the following therapeutic techniques: manual lymph drainage, massage of scar tissue, progressive active and action assisted shoulder exercises along with education. Group B

only received the education. The researchers studied the quality of life questionnaire and volumetric measurements between the two groups. The researchers determined that early active therapy in addition to education is more effective than education alone in preventing lymphedema in post-mastectomy breast cancer patients.

Despite this evidence, a low percentage of survivors received occupational therapy as part of a comprehensive program for survivors age 65 and older (Pergolotti, Deal, Lavery, Reeve, & Muss, 2015). The records of survivors age 65 and older who received care at the University of North Carolina Health Care oncology outpatient clinics between 2009-2013 who also had geriatric assessment data (located in the Carolina Senior Registry) were linked to the University of North Carolina Healthcare (UNCH) administrative database. The resulting dataset of 529 survivors was used to compare the functional data of survivors who received and did not receive occupational therapy (Pergolotti et al., 2015). According to the findings, the odds of having functional deficits increased with age and were higher for those with a high-school diploma versus those with advanced degrees. Of these survivors with functional deficits, only 9% (10/111) received occupational therapy within 12 months of a noted deficit. The findings are profound in that 91% of these survivors were found to have functional deficits with no follow-up care. The functional deficits noted included falls, balance, social, and cognition deficits. This lack of follow-up care puts survivors at an increased risk for functional decline/decreased safety, which can lead to increased hospitalization, decreased tolerance of cancer treatment, and increased health-care costs (Pergolotti, Williams, Campbell, Munoz, & Muss, 2016). Despite occupational therapy being specifically designed to evaluate and treat functional deficits (Accreditation Council for

Occupational Therapy Education, 2016), occupational therapy remains underutilized in cancer care (Pergolotti et al., 2016).

The following section is a summary of the previously mentioned potential co-morbidities that correlate with the American Cancer Society and the American Society of Clinical Oncology breast cancer survivorship recommendations and guidelines (Runowicz et al., 2016). This information is the first step toward providing cancer centers with an opportunity to add an occupational therapy focus to comprehensive breast cancer care.

Breast Cancer-Related Lymphedema and Occupational Therapy

Lymphedema is one of the most dreaded complications of axillary lymph node dissection and has been referred to as “cancer treatment’s dirty little secret” (Mishori, 2010). This is because the condition of lymphedema is not always addressed in health care in a preventative fashion, and survivors only learn of the condition after they acquire it (Choi, et al., 2015; Mishori, 2010; Soran, et al., (2014). Choi, et al., (2015) surveyed survivors' awareness of breast cancer-related lymphedema. Of 116 participants, 81 responded that they had heard of lymphedema, 30 had received explanations about the possibility of lymphedema before surgery, and only 20 patients knew that lymphedema is a non-curable condition, and 24 patients thought lymphedema does not require treatment. This data further supports the need for protocol-driven breast cancer-related lymphedema prevention in the comprehensive cancer program designed for Parkview Regional Medical Center. The National Cancer Institute has made the following statement regarding the lack of understanding of lymphedema as a diagnosis.

Lymphedema is one of the most poorly understood, relatively underestimated, and least researched complications of cancer or its treatment. Lymphedema is an important consideration for clinicians who care for cancer patients because of its relatively high frequency and significant functional and quality of life implications for patients. Lymphedema is an independent predictor of decreased quality of life, even when other predictive factors, such as socioeconomic status, decreased range of motion, age, and obesity is taken into account. (National Cancer Institute, 2016, para. 1).

The percentage of breast cancer survivors diagnosed with lymphedema within the first three years after cancer surgery ranges from 56% to 77% (Rundquist et al., 2015; Soran, et al., 2014). Lymphedema is swelling that occurs when protein-rich lymph fluid accumulates in a body part or extremity (Acebedo, 2015). Breast cancer-related lymphedema is lymphedema (typically in the upper extremity on the ipsilateral side of cancer) that can result from axillary lymph node dissection, chemotherapy, and radiation therapy (Acebedo, 2015). Due to the extremity being edematous, it becomes quite heavy and can be painful (Acebedo, 2015). The heaviness of the arm can limit the survivors' participation in daily activities such as working, cooking, gardening, and childcare. Additionally, the size of the arm often makes finding clothing very difficult and can cause survivors to become very self-conscious of being in public where others may not understand their condition (Acebedo, 2015).

In reviewing the literature, breast cancer-related lymphedema is not only poorly defined, but also not a common talking point with women undergoing breast cancer treatments, despite its high occurrence rate. Incidence rates range from 5% to 56%

within two years of surgery (Dhinakaran, Jain, Benjamin, Kauer, & Dhinakaran, 2014). The vast incidence range also begs for a more consistent definition of lymphedema, which remains an area for further research (Dhinakaran et al., 2014). Krok-Scheon, Oliveri, Kurta, & Paskett (2015) add that our cancer care needs to incorporate earlier detection of lymphedema and that it is important to identify factors that can significantly affect long-term quality of life. Additionally, women who are breast cancer survivors report in survey data that they prefer to have information about breast cancer treatment sequelae, such as lymphedema, in advance so that they have greater awareness (Binkley, 2012).

Interestingly, Stout et al., (2008) reported lymphedema incidence rates with survivors receiving education, surveillance monitoring, and intervention upon volume change as: 21% sub-clinical, 0% stage 1, 2% stage 2 (associated with infection n=2 or metastatic disease n=2). Hayes et al., (2010) reported lymphedema incidence at 33% stage 2 and 3 with no intervention and Armer et al., (2010) reported a 48% incidence stage 2 and 3 without intervention. This data demonstrates the great decrease in lymphedema incidence with taking a preventative, proactive approach via education and surveillance.

Typically, when a woman experiences lymphedema, management of that condition would then take place. For example, if a survivor is diagnosed with breast cancer-related lymphedema, she would be referred to a certified lymphedema therapist (if one is available) to learn management techniques for this chronic and potentially debilitating condition (Brown et al., (2015); Lu et al., 2015). However, the ideal scenario is early identification and conservative treatment that may prevent the condition.

This approach to early identification and management of lymphedema is emerging as a standard of care. The model for care delivery in early identification however relies on adequate and proactive screening that repeats measures from baseline over time to assess for meaningful change (Fransceso, et al., 2017; Gabram, et al., 2009; Soran, Menekse, Girgis, DeGore, and Johnson, 2016; Stout et al., 2012; Stout, 2012)

Without detection and early prevention, the onset of lymphedema can result in complicated medical co-morbidities, decreased quality of life, and increased related financial costs. Thomas, et al., (2015) reported that women who experience breast cancer need to be educated on the possibility of having to adapt to changes to their body and spirit, and the lifelong need to adhere to recommendations after surgery for arm care, exercise, and diet.

Some healthcare providers believe that informing survivors of potentially adverse effects of cancer treatment can create unnecessary fears. True, healthcare providers must be sensitive to survivor's reactions to health information, however, survivors consistently express the need for information before treatment and especially before developing a physical or cognitive impairment (Stout et al., 2012).

At this time, lymphedema cannot be cured and, therefore, becomes a life-long chronic often-debilitating condition. Currently, there is not a definite factor that may explain lymphedema's etiology (Eyigör, Cinar, Caramat, & Unlu, 2015); however, risk factors identified for increasing a survivor's chance of acquiring lymphedema include ipsilateral blood draws, injections, blood pressure readings, and air travel (Ferguson et al., 2016). Prevention and early detection are critical to avoid these potential complications and are an invaluable aspect of comprehensive breast cancer care.

Dominick, Natarajan, Pierce, Madanat, & Madlensky, (2014) reported that prior studies have shown that patient education can prevent the development of lymphedema as well as improve health outcomes among those living with lymphedema. Additionally, these authors discovered that women without lymphedema were more likely to receive pretreatment lymphedema education compared with women with lymphedema. The researchers also reported that participants who received lymphedema education reported fewer breast cancer-related lymphedema symptoms than those who did not receive lymphedema education (Dominick et al., 2014). The research completed by Dominick et al., (2014) supported the inclusion of occupational therapy in a comprehensive breast cancer program, particularly focusing on preventative patient education.

An additional emotional concern for the survivors is the fear of acquiring lymphedema (Jammallo et al., 2014). In a prospective cohort study of 324 survivors undergoing treatment for unilateral breast cancer, researchers concluded that preoperative fear, having a younger age at diagnosis, and sustaining axillary lymph node dissection might contribute to postoperative fear of lymphedema. Jammallo et al., (2014) suggested individualized education that begins preoperatively continues throughout the treatment course and is revisited 24 months postoperatively may help minimize these fears. They reported this information as an implication for nursing because nursing is typically present and active throughout the survivorship. However, the program proposed in the project utilizes occupational therapy services from time of diagnosis. While it is important for nursing to understand the risks involved with breast cancer-related lymphedema, having an occupational therapy team certified in lymphedema on board from the onset of the diagnosis of breast cancer, ensures skilled examination and

assessment of the patient, an accurate differential diagnosis, and prompt detection of subclinical lymphedema and could prevent a diagnosis of lymphedema.

Primary care physicians, oncologists, radiation oncologists, and surgeons should be well aware of the risks of lymphedema and be keenly assessing for early detection. Early diagnosis enables identification and treatment of lymphedema at the earliest onset when it can be managed conservatively as opposed to managing advanced-stage, chronic lymphedema, which entails more intensive and costly care (Stout et al., 2011; Runowicz, et al., 2016). There is no cure; therefore, it is critical to improve breast cancer-related lymphedema risk prediction and prevention. Unfortunately, because the primary focus of breast cancer care is the elimination of cancer, the attention to breast cancer-related lymphedema education/prevention is often not a high priority in cancer treatment, which is leaving a significant gap in care for survivors of breast cancer (Acebedo, 2015).

Soran, et al., (2016) studied the use of L-Dex bioimpedance spectroscopy on the early detection of subclinical lymphedema. They reported that lymphedema was diagnosed by L-Dex bioimpedance spectroscopy earlier than by use of a measurement tape in 75.6% of their patients. Fu et al., (2013) concluded from their research with 250 women, that use of L-Dex bioimpedance spectroscopy might have a role in clinical practice despite its cost, to add confidence in the diagnosis of arm lymphedema among survivors. The researchers explained further that lymphedema is a progressive and debilitating condition and early treatment usually leads to better clinical outcomes. However, they encouraged clinicians to integrate other assessment methods such as self-report, clinical observation, or perometry as well to ensure the most accurate diagnosis of lymphedema (Fu et al., 2013).

Recently clinical practice guidelines have been published that support the need for early intervention. These guidelines advocate for pre-operative measures of the tissue, using an L-dex unit, and prospective ongoing monitoring and screening for the onset of lymphedema. This guideline is not designed as an interventional treatment for lymphedema, but a model for screening for the early signs of the condition and for recommending triage for additional therapy services. (Shah, Chirag, Vicini, & Arthur, 2016).

Jeffs et al., (2016) reported on 740 survivors of breast cancer and concluded that women living with arm dysfunction often experience changes in their ability to enjoy and benefit from a variety of meaningful activities. Addressing participation in meaningful activities, the foundation of occupational therapy treatment could be addressed through occupational therapy intervention.

Health care practitioners, such as occupational therapy practitioners treating survivors with breast cancer-related lymphedema, are often concerned with the survivors' ability to follow their self-care regimen once formal treatment has stopped (Brown et al., 2015). Even if survivors can sufficiently complete their home prescription initially as time goes on, they begin to face compliance issues due to the time and energy consuming nature of caring for a chronic condition. Adherence to self-care activities by survivors with breast cancer-related lymphedema has been shown to be non-optimal (Brown, Cheville, Tchou, Harris, & Schmitz, 2014). Brown et al., (2014) suggested that compliance with self-care is not only non-optimal but also waning over time; therefore, the notion of preventing lymphedema at all costs is supported. It should be noted that many of the psychosocial effects of cancer are also brought about through dealing with

lymphedema. Psychosocial effects of having lymphedema are often isolation and depression (Brown et al., 2014). Many individuals with lymphedema are self-conscious of having their lymphedematous extremity showing in public. This self-image concern can lead to isolation from friends, family, and the community, which in turn can lead to depression.

One area of lymphedema treatment that has been controversial is exercise, particularly strength training, using the lymphedematous extremity. Keilani et al., (2016) used a literature review approach to study the effects of strength exercise on secondary lymphedema in breast cancer. Keilani et al., (2016) reported that none of the articles reviewed demonstrated adverse effects of a resistance exercise intervention on lymphedema status. Looking further into weakness in a lymphedematous limb, researchers evaluated the ratio of significant weakness in the affected upper extremity of survivors with breast cancer-related lymphedema to their non-affected side and evaluated factors that related to arm weakness and physical function. Handgrip strength and the DASH were used to evaluate upper extremity strength and function. Out of 80 survivors studied, 29 survivors or 36.3% had significant weakness in the affected arm; however, weakness was not related to lymphedema itself; rather, it was related to disuse of the extremity out of fear. Additionally, fears of using the extremity and depression significantly contributed to the variance in DASH scores (Lee et al., 2015).

Supporting the provision of exercise and strengthening with survivors with lymphedema and those at risk, is a study of 258 survivors in the Physical Activity and Lymphedema Trial weight-training program (Winters-Stone, Lauder milk, Woo, Brown, & Schmitz, 2014). Winters-Stone et al. (2014) concluded that The Physical Activity and

Lymphedema weight training program increased muscle strength without exacerbating or causing lymphedema among breast cancer survivors, but strengthening was not effective in increasing skeletal health, specifically bone mineral density (Winters-Stone et al., 2014).

One important aspect to consider through survivors' cancer treatment regimen is their perception of success and benefit within the program. Jeffs et al., (2016) studied 21 women with breast cancer-related lymphedema to identify factors that influence their perception of success and benefit with self-management of their lymphedema. Researchers utilized a grounded theory approach and completed in-depth interviews with 21 women. Researchers discovered that the factors affecting the survivors' ability to independently self-manage lymphedema as: establishing a daily routine, recognizing benefit of self-management and consequences of non-treatment, "owning" treatment, knowledge and understanding of lymphedema and treatment, problem solving/dealing with the challenges of lymphedema and treatment, and the time required for treatment (Jeffs et al., 2016). Tasks are to become components of the patient's day, which becomes the survivor's occupation. Occupational therapy practitioners address these types of occupations and ways survivors can be successful with a home lymphedema management program. Without learning independent self-management techniques, the survivors with lymphedema risk further exacerbation, which also increases their risk of cellulitic infections (Jeffs et al., 2016). Therefore, it is imperative that survivors are educated on lymphedema prevention, risk reduction, and management (if diagnosed with lymphedema) throughout survivorship.

Additionally, 16 women with breast cancer-related lymphedema were studied to investigate their perceptions of lymphedema treatment after breast cancer surgery. The following themes were identified as the survivors' perceptions of treatment: uncertainty, disappointment, guilt, safety, and autonomy (Karlsson, Biguet, Johansson, & Nilsson-Wikmar, 2015). Themes are quite important as they could also predict long-term survivor success with self-management. The themes of uncertainty, disappointment, and guilt are all considered negative feelings (Karlsson et al., 2015). It is understandable that if patients were not educated on lymphedema risks and prevention techniques that they could feel disappointed and guilty. The positive emotions of safety and autonomy might be a result of knowing they have an expert (occupational therapy practitioner) that is there to help them. It could be hypothesized that education in prevention could not only decrease the number of survivors with lymphedema but also improve upon these negative feelings as well (Karlsson et al., 2015).

Ridner, et al., (2016) completed a focus group with 21 breast cancer survivors with lymphedema. The researchers discovered that the survivors experience lack of social support, lack of resources for self-care activities, and self-advocacy. The lack of social support included feeling misunderstood, a minimization of their needs, and feeling criticized (Ridner et al., 2016).

Occupational therapy should be an integral part of cancer programs, based on the literature reviews by Hunter et al., (2017); Fleischer and Ito (2016); Pergolotti, et al., (2015); Pergolotti, et al., (2016); and Sleight and Stein-Duker (2016). Occupational therapy practitioners with advanced lymphedema training are educated and trained to provide survivors with education on lymphedema prevention, risk reduction strategies, as

well as lymphedema treatment (Polo & Smith, 2017). Without occupational therapy being an active member of the comprehensive cancer team, their unique skills remain under-utilized.

Lymphedema is just one of the many potential co-morbidities that can occur as the result of breast cancer treatments. Therefore, it is important that women who have been diagnosed with breast cancer learn lifestyle techniques that promote long-term wellness. Examples include an understanding of proper nutritional intake; exercise to keep body mass index in a healthy range; and emotional and cognitive supports, such as support groups and counseling services (Coa et al., 2014).

Breast Cancer-Related Pain and Occupational Therapy

It is estimated that 25% to 60% of breast cancer survivors experience chronic pain (Runowicz et al., 2016). When matched for age, approximately one-third of survivors reported above-average pain compared to non-survivors at 40 months and ten years' post-diagnosis (Runowicz et al., 2016). The pain can be a result of surgery, radiation therapy, chemotherapy, and endocrine therapy (Runowicz et al., 2016).

Pain is a significant concern as it can significantly decrease a survivor's quality of life (Runowicz et al., 2016). Park et al., (2015) concluded that while pain typically decreased after surgery, 26% of survivors continued to report pain as much as five years post surgery, which negatively affects their quality of life. Often, these general neuromuscular disorders and other various physical symptoms, such as pain, (after diagnosed as post-mastectomy pain syndrome) cannot be prevented due to the nature of the surgical intervention. Occupational therapy practitioners can, however, address the pain and decreased range of motion post-surgery. When addressed early, additional

complications can potentially be eliminated, e.g., long-term pain, adhesive capsulitis, decreased functional use of the upper extremity, and a plethora of psychosocial issues that come with impairments (Runowicz et al., 2016). Therefore, comprehensive cancer care emphasizes rehabilitation throughout the cancer treatment process to retain or restore patient's functional status and improve overall quality of life (Park, 2015).

De Groef et al., (2015) studied the effects of postoperative exercising, including active stretching, passive mobilizations, manual stretching, and myofascial therapy for pain and impaired range of motion. It was determined that therapy intervention (stretching and active exercise) postoperatively is effective in decreasing known post-surgical concerns such as pain and impaired range of motion (De Groef et al., 2015). Additionally, occupational therapy practitioners can potentially improve patient's levels and perception of pain as they treat not only the source of the pain but the emotional effects of having chronic pain as it relates to daily tasks and engagement in activity. Occupational therapy practitioners can help the caregivers to understand how pain can affect the survivors' mood and ability to engage with others (De Groef et al. 2015).

Breast Cancer-Related Fatigue and Occupational Therapy

Breast cancer-related fatigue is common for survivors, particularly survivors who underwent radiation therapy and chemotherapy (Runowicz et al., 2016). It has been estimated that 28-91% of cancer survivors experience fatigue (Runowicz et al., 2016) and Polo and Smith (2017) reported that approximately 50% of cancer survivors report that fatigue significantly affects their daily routine, participation in social activities, and overall occupational performance.

Because of the high rate of incidence and because fatigue can continue to affect occupational participation throughout survivorship, it is critical that occupational therapy practitioners screen, assess, and intervene with survivors for fatigue (Braveman & Hunter, 2017).

Rundquist et al., (2015) studied the effects of one-on-one fatigue management with survivors with chronic conditions. Using a one-on-one management course, participants showed significant reductions in fatigue and a significant increase in self-efficacy and quality of life, physical well-being, emotional, and functional well-being. Rundquist et al., (2015) concluded that the possible reason for the beneficial effects of one-on-one management was because it was easier for participants to share their unique challenges and experiences with fatigue versus a group format, enabling a more client-centered intervention (Rundquist et al., 2015).

Occupational therapy practitioners are also experts in the area of activity analysis and energy conservation/work simplification. Expertise in energy conservation and environmental modification enables the occupational therapy practitioner to analyze a survivor's desired activity and modify the activity or the environment to enable the patient to participate, despite varying levels of fatigue (Polo & Smith, 2017).

Occupational therapy practitioners can prescribe individualized energy conservation methods to improve participation in current life roles, engagement in work, and to improve occupational performance (Polo & Smith, 2017).

Therapeutic exercise is often the first choice of therapy for fatigue, however, survivors' low energy level effect their participation in daily activities before the benefits of exercise are manifested McMillan and Newhouse (2011). In a systematic review of

138 studies, Braveman and Hunter (2017) reported strong evidence supporting the benefits of exercise in decreasing fatigue and improving a survivor's quality of life and that this benefit continues for people after radiation therapy or chemotherapy. Further, there was strong evidence to support aerobic exercise to decrease survivor fatigue. Through increased participation in these desired activities, survivors begin to tolerate increased activity and fatigue begins to wane, allowing improved quality of life for the survivor (Sleight & Stein-Duker, 2016; Pergolotti, et al., 2015; Pergolotti et al., 2016).

Cancer-Related Body Image Concerns and Occupational Therapy

Body image changes can be of significant concern for breast cancer survivors, affecting from 31% to 67% of survivors (Runowicz et al., 2016). Many factors contribute to body image concern including amputation of a breast, scarring, lymphedema, loss of hair, sexual dysfunction, chemo-related early menopause, skin changes, and weight changes. Body image can have a significant effect on a survivor's quality of life, particularly for younger breast cancer survivors and survivors who are sexually active (Rundquist et al., 2015). Humans associate a large part of identity with the body, the way it looks, the way it feels, and the way it functions (Stern, 2016). Having difficulty with body image can lead to social isolation, depression, and lack of participation in activities of daily living citation.

Cancer-Related Cognitive Impairment and Occupational Therapy

Change in cognitive function following cancer treatments is widespread (Player, Mackenzie, Willis, & Loh (2014). 75% of active treatment survivors experience cognitive impairment; up to 35% of cancer survivors experience change in cognitive function after treatment has ended, and can persist for as long as 20 years (Runowicz et

al., 2016; Janelins, Kesler, Ahles, and Morrow (2014). Survivors need ways to overcome changes in concentration and memory to ensure participation in occupational therapy engagement (Player et al., 2014). It is important that occupational therapy practitioners screen patients for cognitive impairment and provide treatment to promote ongoing participation in occupations along with education for caregivers Braveman and Hunter (2017).

Cognitive changes often lead to distress, decreased independence and safety with activities of daily living, impaired quality of life, and declines in concentration, executive function, and memory. Changes in cognitive function because of cancer treatments are strongly related to the loss of function in daily roles Player et al., (2014). and the survivor's role within the family, workplace, and society (Runowicz et al., 2016).

In a systematic review of 138 studies, moderate evidence supports using cognitive rehabilitation to improve attention, cognition, and overall quality of life. These findings suggest that occupational therapy practitioners can address the emotional and psychological needs of women enabling them to build their awareness of cognitive changes and thus implement coping and management skills (Braveman and Hunter, 2017) which in turn will assist survivors in returning to daily occupations during or following their cancer treatments (Player et al., 2014).

Cancer-Related Distress, Fear of Reoccurrence, Depression, Anxiety and Occupational Therapy

As breast cancer survivors attempt to return to normalcy in their daily lives, they often experience fear of cancer recurrence, which can contribute to mental health concerns, such as distress, depression, and anxiety (Runowicz et al., 2016). Additionally,

having more symptoms, especially pain, have been related to a higher level of having a fear of reoccurrence (Runowicz et al., 2016).

According to the findings of a systematic review of observation studies, the prevalence of depression and anxiety is 22% with a range of 13% to 56% (Runowicz et al., 2016). Braveman and Hunter (2017) reported finding strong evidence that cognitive-behavioral and educational interventions were found to decrease anxiety and depression in the short term. Devereaux and Carlson (1992) stated that because occupational therapy has an explicit focus on roles, behaviors, and adaptive skills, they (occupational therapy practitioners) could play a key role in the treatment of depression and anxiety associated with cancer.

When delivering occupational therapy during survivorship, Hwang, Lokietz, Lozano, & Parke (2015) recommended that a client-centered evaluation begin with an occupational history interview emphasizing the client's strengths and coping strategies followed by a careful assessment of limitations in various occupations and roles within the context of the client's lifestyle demands and choices. Wide-ranging approaches can be integrated into the client's holistic treatment plan to improve various symptom specific problems and occupation-based issues, such as:

- coping and relaxation techniques
- leisure programs
- cognitive strategies
- activity and work adaptation
- assistive technology to optimize performance in activities of daily living
- education

- volunteer groups for preventing social isolation and promoting psychosocial well-being
- and lifestyle consultation for enhancing health and quality of life (Hwang et al., 2015)

Breast Cancer-Related Bone/Musculoskeletal Health and Occupational Therapy

Cancer treatments, such as chemotherapy, can result in an increased rate and severity of bone loss. Up to 80% of survivors' experience bone loss (Runowicz, et al., 2016). Bone loss risk factors are increased when combined with other known risk factors including advanced age, prior fracture history, and family history of fractures. Lifestyle related risk factors exacerbating chemo therapy-induced bone loss include smoking, excess alcohol, sedentary lifestyle, low calcium, and vitamin D deficiency (Runowicz et al., 2016).

Runowicz (2016) suggested providing education to decrease the morbidity associated with bone loss. The education should include education about risk factors and a healthy lifestyle, physical activities, weight-bearing exercises, and education about the harms of tobacco use and excessive alcohol intake.

Cancer treatments can also result in multiple musculoskeletal changes (Runowicz et al., 2016) including decreased use/pain of ipsilateral upper extremity after surgery, decreased range of motion, rotator cuff injury, adhesive capsulitis, and axillary web syndrome. The conditions can result in decreased participation in activities of daily living and therefore a decline in quality of life (Runowicz et al., 2016).

Dobek, Winters-Stone, Bennett, & Nail, (2014) previously studied the effects of one year of supervised resistance plus impact training on bone loss and muscle strength in

older breast cancer survivors. At the one-year follow-up study their data suggested that spine bone mass density could be preserved in older breast cancer survivors even after formal exercise training stops; however, muscle strength is not equally maintained and may require continued participation in a supervised exercise program. Thus, Dobek et al., (2014) concluded that cancer survivors exercise programs aimed at improving musculoskeletal health be considered in the long-term care plan.

Breast Cancer-Related Sexual Health and Occupational Therapy

Sexually related side effects from cancer treatments include sexual desire disorder/decreased libido (23%-64% of survivors), arousal or lubrication concerns (20%-48% of survivors), orgasmic concerns (16%-36% of survivors), and dyspareunia (35%-38% of survivors) (Runowicz et al., 2016). Sexual health concerns can decrease quality of life for the survivors and their respective partners resulting in a decreased quality of life for both (Runowicz et al., 2016).

Couldrick (2005) provided strategies for occupational therapy practitioners to use with their clients to achieve improved quality of life by improved sexual health.

Strategies include the following:

- validation of survivors' sexuality by acknowledging and affirming the importance, relevance or priority that they may attach to intimacy and sexual expression
- listening to survivors' sexual concerns, if they wish to discuss them, by providing sensitive permission-giving strategies

- addressing issues that fall within occupational therapy competency (for example, improving access to social opportunities, fatigue management, role realignment and the provision of information on equipment)
- providing information on, or referring clients to, appropriate agencies
- advocating for better sexual health services if necessary (for example, when existing psychosexual health services are inaccessible)

Cancer-Related Psychosocial/Spiritual Comorbidity and Occupational Therapy

For many survivors, cancer treatments save their lives, but leave them with deficits in psychosocial well-being. The most frequently reported areas of psychosocial deficits were the reluctance to start new relationships, worrying about family members' health, avoiding social situations, feeling fearful, and feeling depressed (Hwang et al., 2015). The investigators concluded that occupational therapy practitioners are well equipped with knowledge and skills for maximizing a survivors' quality of life by addressing survivors' occupational performance (Hwang et al., 2015). The researchers also offered the following principles and strategies that can be applied to the delivery of occupational therapy:

- energy conservation
- coping and relaxation techniques
- exercise
- leisure program
- cognitive strategies
- activity and work adaptation
- assistive technology to optimize performance in activities of daily living

Sadati et al., (2015) studied religion as an empowerment context with women diagnosed with breast cancer. They reported that religious concepts or beliefs and behaviors associated with religion are heightened with regards to interpretation and understanding of having cancer, coping with cancer, and gaining a new concept for life and death. Maley, Pagana, Velenger, & Keiter-Humbert, (2016) studied major life events and transitions and those effects on spirituality. The researchers reported that occupational therapy has a unique role in and contribution to the team approach in addressing spirituality, particularly the influence of occupations on the experience of spirituality and even potentially the meaning of spirituality as it relates directly to occupational engagement. Occupational therapists can use occupations within their interventions to elicit meaning and facilitate the experience of spirituality (Maley et al., 2016).

Cancer-Related Work/Productivity/Financial Stress as Co-Morbidity and Occupational Therapy

Breast cancer diagnosis is often made during a time in life when the survivor is professionally active. Returning to work after breast cancer treatments is important from a societal as well as individual point of view (Tiedtke et al., 2012). As recovery rates for breast cancer increase, more women are confronted with the incapacity to return to work (Tiedtke et al., 2012). Additionally, cancer survivors can experience difficulties returning to work and accomplishing a level of productivity similar to their healthy counterparts due to the physical and emotional changes (Feuerstein, 2005). In addition to lost wages, patients also fear costs related to the medical treatment of cancer both during treatment and throughout survivorship (Shaitelman et al., 2015).

Many employees with breast cancer do not feel adequately supported in the return to work process; furthermore, these women experience their work incapacity in very different ways, highlighting the need for an individual and flexible approach from all professionals involved in the return to work process (Tiedtke et al., 2012). Examples of experiences in work incapacity include feelings of uncertainty and a loss of control over their job, some experience the need to work throughout their treatments out of loyalty to their employer or financial concerns, and some experience discriminating attitudes from their colleagues (Tiedtke et al., 2012). An individual and flexible approach from employers could include the use of creativity for work scheduling and an understanding that the experience of breast cancer is different for each survivor and some may be able to work through treatments while others are too debilitated (Tiedtke et al., 2012).

In the opinion of the experts, return to work is an essential part of the rehabilitation of survivors that should be offered as a part of comprehensive cancer care (Desiron, Donceel, deRijk, & Van Hoof, 2013). In a legal and societal environment that supports return to work, Desiron et al., (2013) believed that goal setting for the return to work process guided by occupational therapy practitioners should be embedded in an integrated, holistic, and client-centered cancer program. Additionally, the goal setting should focus on abilities of the patient and linked to the total quality of life of the survivors, and must include workplace visits and observations of the patient's situation. Returning survivors to productive work roles can be a large part of the solution to the financial stress and concern the survivors face (Desiron et al., 2013).

Braveman & Hunter (2017) provide further support for the inclusion of occupational therapy in a return to work program. They found moderate evidence

supporting using high-intensity physical training for survivors wanting to maintain or restore work-related abilities after cancer treatments and the use of multidisciplinary interventions including physical, psychological, and vocational components for survivors (Braveman & Hunter, 2017).

Breast Cancer-Related Survivorship and Occupational Therapy

Occupational therapy practitioners are highly educated and well trained in the areas of health promotion and wellness therefore prepared to address the physical and mental needs of survivors dealing with a diagnosis of cancer (Accreditation Council for Occupational Therapy Education; Standards B.1.1 & B.1.3, 2016). Additionally, a focus on education is also provided in the Occupational Therapy in the Promotion of Health and the Prevention of Disease and Disability Statement (2001). The statement defines health promotion as “any planned combination of educational, political, regulatory, environmental, and organization supports for action and conditions of living conducive to the health of persons, groups, or communities” (American Occupational Therapy Association, 2001, p. 1). The statement defined wellness as “a dynamic way of life that involves actions, values, and attitudes that support or improve both health and quality of life” (American Occupational Therapy Association, 2001, p. 1) The statement additionally categorized prevention into three levels: primary, secondary, and tertiary. Primary prevention is “education or health promotion designed to assist survivors to avoid the onset of unhealthy conditions, diseases, or injuries” (American Occupational Therapy Association, 2001, p. 1). Secondary prevention includes early detection and treatment designed to prevent or disrupt the disabling process. Tertiary prevention refers to treatment and services designed to arrest the progress of a condition, prevent further

disability and promote social opportunity (Occupational Therapy in the Promotion of Health and the Prevention of Disease and Disability Statement, 2001).

The American Occupation Therapy Association (AOTA, 2001) supported the occupational therapy profession's role in disability prevention and health promotion through "The Guide to Occupational Therapy Practice." "Occupational therapy practitioners are trained to provide prevention, health promotion, and wellness at the individual and population levels" (AOTA, 2001, p. 1). This specialized training puts occupational therapy practitioners in the forefront for providing preventative, health promotion, and wellness services to cancer survivors.

Given an occupational therapy practitioner's role in prevention, health promotion, and wellness, they can effectively combine this with their thorough understanding of the relationship of their survivors' roles, daily occupations, and their environment. Understanding the holistic nature of their survivors' needs paired with the use of occupation-based treatment allow for a comprehensive approach to both prevention and treatment of breast cancer-related lymphedema (Campbell, 2016). As a profession, occupational therapy has laid claim to meaningful occupations as its domain and has included health promotion and wellness within this scope of practice (Hildenbrand & Lamb, 2013). The educational skills acquired by occupational therapy practitioners combined with their understanding of occupation provides a thorough foundation to deliver education to cancer survivors throughout all stages of their care. Prevention, health promotion, and wellness are the foundations of care for survivors (Runowicz et al., 2015) and should be continually addressed throughout the survivor's life span. One means of addressing survivor status is through the use of the BREAST-Q. The

BREAST-Q is a validated instrument that uses specific patient-reported measures to evaluate and quantify the success of breast surgeries from the patient's perspective (Shekhawat et al., (2015).

The side effects of cancer treatments have a significant impact on an individual's level of function. The incidence rates of these functional deficits suggest that they are common problems inherent in most cancer treatments. Up to 80% of survivors will regain full life expectancy, therefore, they should do so with full functional abilities, free from disability from cancer treatments (Stout, 2012).

There is ample evidence to support occupational therapy-based interventions that may mitigate many of these sequelae as well as to rehabilitate individuals who experience functional decline. In the presence of such evidence it is prudent to suggest that a model of care that proactively uses occupational therapy services to engage individuals in meaningful educational interventions and screen them for functional changes would be of benefit to this population that is at high risk for encountering functional decline during treatment. Such a model requires a different perspective on traditional rehabilitation restorative care. Dietz (1981) outlined phases of cancer rehabilitation and cited the need for preventive rehabilitation as an important component that could help to prevent or mitigate the negative impact of treatment-related side effects on function. The findings identified in this section support that a prospective model of care, using occupational therapists could be beneficial for screening cancer patients for emerging impairments and triaging them for additional episodic care once deficits are identified. This premise serves as the basis for the model recommended in this project.

Further, the existing model of care for survivors with breast cancer focuses on treatment of the disease, followed by continuing surveillance to detect recurrence (Stout et al., 2012). This approach lacks attention to survivors physical and functional well-being from the time of diagnosis throughout their survivorship. Evidence supports prospective surveillance for early identification and treatment as a means to prevent or mitigate many of the comorbidities associated with breast cancer (Stout et al., 2012). In oncology rehabilitation, prospective surveillance has been defined as a proactive approach to intermittently examining survivors' and providing ongoing assessment during and after disease treatment, often in the absence of impairment, in an effort to enable early detection of and intervention for impairments known to be associated with cancer treatment (Stout, 2012).

The goals of the prospective surveillance model are:

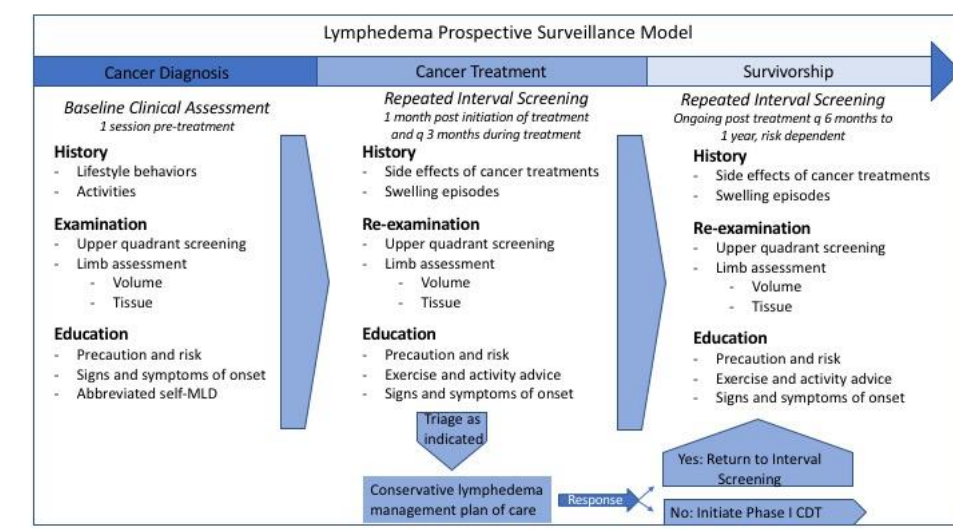
- To promote surveillance for common physical impairments and functional limitations associated with breast cancer treatment.
- To provide education to reduce risk or prevent adverse events and facilitate early identification of physical impairments and functional limitations.
- To introduce rehabilitation and exercise interventions when physical impairments are identified.
- To promote and support physical activity, exercise, and weight-management behaviors through the trajectory of disease treatment and survivorship (Stout et al., 2012).

The prospective surveillance model is not a stand-alone, independent model as it is designed to be incorporated into existing multidisciplinary survivorship care (Stout

et al., 2012). There are two primary components of the prospective surveillance model generalized from the chronic care model, which are: 1) impairment identification and management, including co-management of treatment effects with other members of the oncology care team; 2) health-promoting skills and behaviors (Stout et al., 2012).

Additionally, the prospective surveillance model is designed to reduce the need for intensive rehabilitation and therefore decrease overall financial medical burden. For example, the cost to manage early-stage breast cancer-related lymphedema per survivor per year using a prospective surveillance model is \$636.19. The cost to manage late-stage breast cancer-related lymphedema per survivor per year using a traditional rehabilitation model is \$3124.92 (Stout et al., 2012). The prospective surveillance model is emerging as the standard of care in breast cancer treatment and requires a shift in the paradigm of rehabilitation from a reactive approach to a proactive approach.

Example of a Lymphedema Prospective Surveillance Model:



(Stout et al., 2012)

Chapter 3 discusses the methods that were used to meet the objectives of this capstone project that include planning and designing the program and program evaluation.

The proposed program was designed specifically to be integrated into Parkview Regional Medical Center, located in Fort Wayne, Indiana, in a new, state-of-the-art, patient-centered cancer facility. The new cancer institute spans over 125,000 square feet, budgeted to cost \$80 million, and expected to open the end of 2017 (Packnett, 2015). The hospital has set a goal to be the best cancer provider in the area by focusing on providing patients with a healing environment that promotes comfort, hope, and confidence (Packnett, 2015). Working to achieve this, the cancer center will use natural lighting, private spaces for families, and respite rooms (Packnett, 2015). Additional goals of the facility include being able to provide all needed cancer services in one facility, improve patient flow, offer convenient access to the services, and plans to work with the Mirro Center for Research to increase the number of clinical trials available for the patients (Packnett, 2015). Additionally, after meeting with the Parkview Regional Medical Center's breast cancer team, it was clear that occupational therapy services were included in the plan for the new cancer institute. The extent to the inclusion of occupational therapy services will be further determined after review of this proposed program.

The planning portion of this capstone project included utilizing various actions to learn what the components of a comprehensive breast cancer program include along with learning which of these components are missing in Parkview Regional Medical Center's current breast cancer program. The activities completed included a literature review,

meetings with Parkview Regional Medical Center's breast cancer team members, interviews with experts, completion of an on-site residency, attendance at an international cancer rehabilitation summit, completion of continuing education courses, and conducting a focus group with breast cancer survivors.

The data collected was then compiled and analyzed in order to condense and summarize, to determine the components of best practice that are missing from Parkview Regional Medical Center's current breast cancer program. The data was then studied in order to create a comprehensive, innovative, and evidenced-based occupational therapy breast cancer program that is protocol-driven but designed with the ability to remain client-centered and individualized.

The literature review focused on learning what best practice entails for breast cancer survivors and what the top cancer centers in the United States provide as best practice. Additionally, the literature review provided information on the role of occupational therapy in the intervention of potential co-morbidities such as lymphedema, pain, fatigue, body image, cognitive impairment, distress/fear/depression/anxiety, bone/musculoskeletal health, psychosocial/spiritual concerns, work/productivity/financial concerns, and long-term needs through survivorship. The literature review also consisted of learning which theories and models could best support the goals of the proposed program.

Parkview Regional Medical Center's Stakeholders

A meeting with Parkview Regional Medical Center's breast cancer team was conducted by the primary investigator on May 24, 2016 to obtain information from administration and the breast cancer interdisciplinary team, to learn what changes they believe could be made to the current breast cancer program to improve survivor care and

quality of life. The individuals present for the meeting included the Senior Vice President of the Cancer Center, the Medical Director and Breast Surgeon, the breast care team of nurses, occupational and physical therapists, and the dietician. Questions asked of the team include:

- What do you currently see as the strengths of your breast cancer program?
- What do you see as potential areas for improvement in your program?
- In a dream world where cost was not a concern, how would you envision the program?
- What services do you feel could be added to improve the program for survivors?
- Do you believe the services you currently provide are consistent and if not, please explain how you think the process could be improved?
- Any other thoughts you have about your breast cancer program you would like to share?

Expert Interviews

Interviews were completed over the phone with two occupational therapists who are cancer experts, working solely with cancer survivors at M.D. Anderson in Houston. One of the occupational therapists is in charge of compliance; the other is the director of rehabilitation and author of The AOTA Practice Guidelines Series titled, “Occupational Therapy Practice Guidelines for Cancer Rehabilitation with Adults” (Braveman & Hunter, 2017). They were asked questions specific to their areas of specialty practice and provided opportunity for open-ended feedback (Appendix A). Additionally,

telephone interviews were completed with a physical therapist who specializes in breast cancer rehabilitation and research.

Another telephone interview was completed with a doctor of philosophy-trained psychometrician who previously worked for Florida Hospital as the Academic Director for the Graduate Medical Education Department. At the time of this appointment, he conducted cancer support groups and worked frequently with medical residents and their breast cancer survivors. The questions focused on his thoughts on gaps in the provision of breast cancer care and how improvements could be made overall (Appendix B).

Residency

An on-site residency was completed at Florida Hospital in Orlando Florida. Florida Hospital is one of the country's largest not-for-profit health care providers with 22 campuses serving communities throughout Florida (Florida Hospital, 2017). Florida Hospital Orlando is a 2,247-bed acute-care medical facility and a member of Adventist Health System (Florida Hospital, 2017). Additionally, this hospital treats more patients than any other hospital in the US (Florida Hospital, 2017). This residency site is accredited by the National Accreditation Program for Breast Centers and has a robust breast cancer program with their mammography centers screening 55,138 women in 2015 (Florida Hospital, 2017). Breast cancer care coordinators assisted 362 newly diagnosed patients and referred 894 patients to the breast cancer care team in 2015 (Florida Hospital Cancer Institute, 2017).

The 30-hour residency experience, spanning three days (September 13-15, 2016), was supervised by Helen Roorda, Director of Florida Hospital's Orlando Cancer Institute.

The residency included spending time with many members of the cancer team during which time the one on one interviews were conducted.

International Cancer Rehabilitation Summit

The International Cancer Rehabilitation Summit provided by Kessler Rehabilitation and co-sponsored by Select Medical and the American Cancer Society was attended by the primary investigator on November 11-13, 2016, in Arlington Virginia. This continuing education course was chosen because the content area focused specifically on rehabilitation for survivors with cancer (Appendix C). The course was designed to assist health care practitioners to gain knowledge and insight into improving their patients' function and quality of life.

Continuing Education

On-line continuing education was completed through the American Occupational Therapy Association. Courses completed include:

- Health Literacy: Effective Client Communication and Education
- Cancer Series Module 1: Impact of Psychosocial Aspects of Cancer on Occupational Engagement
- Cancer Series Module 2: Lymphedema and Breast Cancer
- Occupational Therapy's Contribution to Cancer Rehabilitation
- Exploring the Occupational Therapy Practice Framework

These courses were chosen for their advanced cancer content, ability to improve health literacy within the program and their focus on breast cancer care developed using the Occupational Therapy Practice Framework (American Occupational Therapy Association 2014). The course titled, Health Literacy: Effective Client Communication

and Education (Miller-Scott, 2015) guided the survivor handout portion of the program by ensuring that the handouts avoided medical jargon and acronyms and used plain and simple language for instructions. Additionally, this course encourages the use of the teach back method for communicating with clients and caregivers to ensure comprehension (Miller-Scott, 2015).

The Cancer Series Module 1: Impact of Psychosocial Aspects of Cancer on Occupational Engagement (Lyons, 2015), provided support for occupational therapy practitioners treating the top three psychosocial challenges for individuals with cancer (distress, depression, and anxiety), and supported the proposed program's format for ongoing yearly surveillance of survivors. Lyons (2015) stated, "Psychosocial issues can arise at any point in time, from the moment of cancer screening through diagnosis, treatment, and the balance of life." Additionally, Lyons (2015) spoke to the fact that untreated distress can result in poor compliance with cancer treatments and a lower probability of implementing healthy behaviors.

The Cancer Series Module 2: Lymphedema and Breast Cancer for OT Practitioners (Campbell, 2016) provided guidance to the selection of education to be provided to the survivors. The module supported the following educational aspects of the purposed program: deep breathing, lymphedema prevention, mastectomy exercises, stress reduction and relaxation, energy conservation, and the importance of good posture for recovery (Campbell, 2016).

The continuing education course completed titled, Occupational Therapy's Contribution to Cancer Rehabilitation (Campbell, Hughes, & Munoz, 2016), reinforced the importance of occupational therapy's role in cancer rehabilitation starting when the

cancer diagnosis is made. The course supported providing intervention pre and post-operatively as a means to prevent or limit the occurrence or progression of barriers to performance in context. Additionally, the course reinforced the importance of ensuring that any occupational therapy cancer program remains survivor-centered with meaningful and realistic goals (Campbell et al., 2016). The authors also support use of the Rivermead Behavioral Memory Test for assessing survivor's cognitive status (Campbell et al., 2016).

Support for the intervention approach of the proposed program is provided by the structure of the Occupational Therapy Practice Framework: Domain and Process (American Occupational Therapy Association 2014). Amini (2014) described approaches to intervention that include create/promote (health promotion), establish/restore (remediation, restoration), maintain, modify (compensation, adaptation), and prevent (disability prevention). These approaches are embedded throughout the program from prevention in Stage 1, maintenance, remediation, restoration, and modification in Stage 2 and creation/promotion in Stage 3 (Amini, 2014).

Survivor Focus Group

When considering the design of the program, it was of utmost importance to learn about the attitudes, experiences, feelings, beliefs, viewpoints and involvement in care from survivors who received treatment from Parkview Regional Medical Center's Breast Cancer Program. The format of a focus group provided a means of data gathering that could not be obtained through other methods such as observation or surveys. The results of the focus group had significant impact on the design of the program. Because the majority of the survivors spoke to not receiving similar care or consistent care, the

program was designed to be protocol driven. Survivors spoke about the breast cancer manual they received being daunting; therefore the program provides some general educational hand-out materials that are typically pertinent to all individuals undergoing breast cancer surgery. However, the occupational therapy practitioner has the clinical autonomy to provide the survivor with individualized educational material to meet the survivor's needs. The survivors described that they felt somewhat lost when treatment ended and they were expected to return to their normal daily lives. They made the point that their lives would never be what they used to be. Therefore, the proposed program provides for yearly surveillance by the occupational therapy department to confer with the survivor to ensure that there are no new or ongoing unmet needs.

Chapter 3: Methods

Chapter 3 discusses the methods that were used to meet the objectives of this capstone project that include planning and designing the program and program evaluation.

Design

The proposed program was designed specifically to be integrated into Parkview Regional Medical Center, located in Fort Wayne, Indiana, in a new, state-of-the-art, patient-centered cancer facility. The new cancer institute spans over 125,000 square feet, budgeted to cost \$80 million, and expected to open the end of 2017 (Packnett, 2015). The hospital has set a goal to be the best cancer provider in the area by focusing on providing patients with a healing environment that promotes comfort, hope, and confidence (Packnett, 2015). Working to achieve this, the cancer center will use natural lighting, private spaces for families, and respite rooms (Packnett, 2015). Additional goals of the facility include being able to provide all needed cancer services in one facility, improve patient flow, offer convenient access to the services, and plans to work with the Mirro Center for Research to increase the number of clinical trials available for the patients (Packnett, 2015). Additionally, after meeting with the Parkview Regional Medical Center's breast cancer team, it was clear that occupational therapy services were included in the plan for the new cancer institute. The extent to the inclusion of occupational therapy services will be further determined after review of this proposed program.

The planning portion of this capstone project included utilizing various actions to learn what the components of a comprehensive breast cancer program include along with

learning which of these components are missing in Parkview Regional Medical Center's current breast cancer program. The activities completed included a literature review, meetings with Parkview Regional Medical Center's breast cancer team members, interviews with experts, completion of an on-site residency, attendance at an international cancer rehabilitation summit, completion of continuing education courses, and conducting a focus group with breast cancer survivors.

The data collected was then compiled and analyzed in order to condense and summarize, to determine what components of best practice are missing from Parkview Regional Medical Center's current breast cancer program. The data was then studied in order to create a comprehensive, innovative, and evidenced-based occupational therapy breast cancer program that is protocol-driven but designed with the ability to remain client-centered and individualized.

Summary of Literature Review

The literature review focused on learning what best practice entails for breast cancer survivors and what the top cancer centers in the United States provide as best practice. Additionally, the literature review provided information on the role of occupational therapy in the intervention of potential co-morbidities such as lymphedema, pain, fatigue, body image, cognitive impairment, distress/fear/depression/anxiety, bone/musculoskeletal health, psychosocial/spiritual concerns, work/productivity/financial concerns, and long-term needs through survivorship. The literature review also consisted of learning which theories and models could best support the goals of the proposed program.

Parkview Regional Medical Center's Stakeholders

A meeting with Parkview Regional Medical Center's breast cancer team was conducted by the primary investigator on May 24, 2016 to obtain information from administration and the breast cancer interdisciplinary team, to learn what changes they believe could be made to the current breast cancer program to improve survivor care and quality of life. The individuals present for the meeting included the Senior Vice President of the Cancer Center, the Medical Director and Breast Surgeon, the breast care team of nurses, occupational and physical therapists, and the dietician. Questions asked of the team include:

- What do you currently see as the strengths of your breast cancer program?
- What do you see as potential areas for improvement in your program?
- In a dream world where cost was not a concern, how would you envision the program?
- What services do you feel could be added to improve the program for survivors?
- Do you believe the services you currently provide are consistent and if not, please explain how you think the process could be improved?
- Any other thoughts you have about your breast cancer program you would like to share?

Expert Interviews

Interviews were completed over the phone with two occupational therapists who are cancer experts, working solely with cancer survivors at M.D. Anderson in Houston. One of the occupational therapists is in charge of compliance; the other is the director of

rehabilitation and author of The AOTA Practice Guidelines Series titled, “Occupational Therapy Practice Guidelines for Cancer Rehabilitation with Adults” (Braveman & Hunter, 2017). They were asked questions specific to their areas of specialty practice and provided opportunity for open-ended feedback (Appendix A). Additionally, telephone interviews were completed with a physical therapist who specializes in breast cancer rehabilitation and research.

Another telephone interview was completed with a doctor of philosophy-trained psychometrician who previously worked for Florida Hospital as the Academic Director for the Graduate Medical Education Department. At the time of this appointment, he conducted cancer support groups and worked frequently with medical residents and their breast cancer survivors. The questions focused on his thoughts on gaps in the provision of breast cancer care and how improvements could be made overall (Appendix B).

Residency

An on-site residency was completed at Florida Hospital in Orlando Florida. Florida Hospital is one of the country’s largest not-for-profit health care providers with 22 campuses serving communities throughout Florida (Florida Hospital, 2017). Florida Hospital Orlando is a 2,247-bed acute-care medical facility and a member of Adventist Health System (Florida Hospital, 2017). Additionally, this hospital treats more patients than any other hospital in the US (Florida Hospital, 2017). This residency site is accredited by the National Accreditation Program for Breast Centers and has a robust breast cancer program with their mammography centers screening 55,138 women in 2015 (Florida Hospital, 2017). Breast cancer care coordinators assisted 362 newly diagnosed

patients and referred 894 patients to the breast cancer care team in 2015 (Florida Hospital Cancer Institute, 2017).

The 30-hour residency experience, spanning three days (September 13-15, 2016), was supervised by Helen Roorda, Director of Florida Hospital's Orlando Cancer Institute. The residency included spending time with many members of the cancer team during which time the one on one interviews were conducted.

International Cancer Rehabilitation Summit

The International Cancer Rehabilitation Summit provided by Kessler Rehabilitation and co-sponsored by Select Medical and the American Cancer Society was attended by the primary investigator on November 11-13, 2016, in Arlington Virginia. This continuing education course was chosen because the content area focused specifically on rehabilitation for survivors with cancer (Appendix C). The course was designed to assist health care practitioners to gain knowledge and insight into improving their patients' function and quality of life.

Continuing Education

On-line continuing education was completed through the American Occupational Therapy Association. Courses completed include:

- Health Literacy: Effective Client Communication and Education
- Cancer Series Module 1: Impact of Psychosocial Aspects of Cancer on Occupational Engagement
- Cancer Series Module 2: Lymphedema and Breast Cancer
- Occupational Therapy's Contribution to Cancer Rehabilitation
- Exploring the Occupational Therapy Practice Framework

These courses were chosen for their advanced cancer content, ability to improve health literacy within the program and their focus on breast cancer care developed using the Occupational Therapy Practice Framework (American Occupational Therapy Association 2014). The course titled, Health Literacy: Effective Client Communication and Education (Miller-Scott, 2015) guided the survivor handout portion of the program by ensuring that the handouts avoided medical jargon and acronyms and used plain and simple language for instructions. Additionally, this course encourages the use of the teach back method for communicating with clients and caregivers to ensure comprehension (Miller-Scott, 2015).

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The Cancer Series Module 2: Lymphedema and Breast Cancer for OT Practitioners (Campbell, 2016) provided guidance to the selection of education to be provided to the survivors. The module supported the following educational aspects of the purposed program: deep breathing, lymphedema prevention, mastectomy exercises,

stress reduction and relaxation, energy conservation, and the importance of good posture for recovery (Campbell, 2016).

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Supporting the intervention approach of the proposed program is provided by the structure of the Occupational Therapy Practice Framework: Domain and Process (American Occupational Therapy Association 2014). Amini (2014) described approaches to intervention that include create/promote (health promotion), establish/restore (remediation, restoration), maintain, modify (compensation, adaptation), and prevent (disability prevention). These approaches are embedded throughout the program from prevention in Stage 1, maintain, remediation, restore, and modify in Stage 2 and create/promote in Stage 3 (Amini, 2014).

Focus Group

When considering the design of the program, it was of utmost importance to learn about the attitudes, experiences, feelings, beliefs, viewpoints and involvement in care

from survivors who received treatment from Parkview Regional Medical Center's Breast Cancer Program. Using the format of a focus group provided a means of data gathering that could not be obtained through other methods such as observation or surveys. The results of the focus group had significant impact on the design of the program. Because the majority of the survivors spoke to not receiving similar care or consistent care, the program was designed to be protocol driven. Survivors spoke about the breast cancer manual they received being daunting, therefore the program provides some general educational hand-out materials that are typically pertinent to all individuals undergoing breast cancer surgery, however, the occupational therapy practitioner has the clinical autonomy to provide the survivor with individualized educational material to meet the survivor's needs. The survivors described that they felt somewhat lost when treatment ended and they were expected to return to their normal daily lives. They make the point that their lives will never be what they used to be. Therefore, the proposed program provides for yearly surveillance by the occupational therapy department to confer with the survivor to ensure that there are no new or ongoing unmet needs of the survivor.

Chapter 4: Results

The program that was developed for Parkview Regional Medical Center incorporates recommendations from the literature, Parkview Regional Medical Center's stakeholders, interviews with experts, on-site residency, the International Cancer Rehabilitation Summit, knowledge gained from continuing education, survivor focus group feedback, and the application of the chosen theoretical models and frameworks. The proposed program, including the protocol, procedures, and program evaluation will be presented below.

Theoretical Foundations

It was envisioned that the occupational therapy practitioner would be educating the survivor from the pre-operative stage through survivorship. Therefore, use of a theory to guide the education component was key along with the combining of a model that supports the survivor throughout their journey, a model that guides the four-stage process from a medical standpoint, and an occupational model to guide evaluation and intervention throughout all stages.

The Adult Learning Theory was chosen for the proposed program for its capacity to meet the learning needs of the adult survivors. The Adult Learning Theory has been incorporated throughout the educational aspects of the comprehensive occupational therapy breast cancer program. Adults are ready to learn when there is a clear, meaningful, and perceived need to learn and adults benefit most from an atmosphere of collaboration and mutual respect with the educational provider (Breese & French, 2012; Green & Ellis, 1997; McNeil, Hughes, Toohey, & Dowton, 2006; M. Puliyl, J. Puliyl, & U. Puliyl, 1999). This aspect coordinates well with the design of the program because

the education provided is designed to be survivor-specific and completed in an atmosphere of collaboration between the survivor and the occupational therapy practitioner.

In addition to the use of the Adult Learning Theory, the teach-back method has been incorporated to ensure the educational components of the program are successful. Tamaura-Lis (2013, p. 267) stated, “One of the most promising and successful, evidence-based methods of patient education is the teach-back method” additionally, “it can and should be utilized by any member of the health care team” (2013, p. 270). Teach-back is used to ensure that the health care practitioner has explained the required information in such a way that patients can comprehend it correctly (Tamura-Lis, 2013). Patient comprehension is confirmed when they can restate or reproduce the required information in their own words (Tamura-Lis, 2013). The teach-back method aligns with the program as all education is designed to be taught in a teach-back manner. The occupational therapy practitioner will provide education and physical demonstration (if appropriate) and then ensure learning has occurred when the education is verbalized or demonstrated back to them by the survivor. An important aspect of using the teach-back method is ensuring that the information being taught is at the literacy level of the patient or primary learner (Tamura-Lis, 2013). Through use of the teach-back method, health care providers can evaluate whether learning has occurred and if not, they can revise their teaching method as needed (Tamura-Lis, 2013; Haney & Shepherd, 2014). Additionally, through use of the occupational profile embedded in each occupational therapy evaluation, the healthcare practitioner will have a very good understanding of the survivors learning needs.

The Empowerment Model was chosen for its capacity to provide a structure to the program to enhance the survivors' ability to engage and take control over their new life circumstances while working towards healthy life-long survivorship goals (Fisher & Howell, 2010). This model, particularly when combined with using adult learning theory principles supports the proposed program's goal of decreasing risk of potential co-morbidities and improving long-term survivorship health status. From an occupational therapy practitioner viewpoint, use of empowerment throughout the proposed program, focuses on the ability of the individual facing difficult life circumstances to define and actively engage in solutions to their problems (Peterson, 2014).

The foundation of empowerment is woven through the proposed program through educating the survivor to be proactive versus reactive. This is achieved through the preventative measures taught to the survivor, such as learning new healthy behaviors like following lymphedema precautions. The empowerment model is also evidenced throughout the program through the focus on the survivor's goals and the education they need to be successful not only in the stage of the protocol they are currently in, but throughout their entire survivorship. Learning occurs at each stage of the proposed program in order to empower the survivor with knowledge to be able to take control of their life and make healthy changes throughout survivorship.

In an attempt to ensure consistency of care, the peri-operative home model, which is modeled after the Medical Home Model, was chosen as a foundation to create the stages of the protocol (American Society of Anesthesiologists, 2014; Gentile, 2017). This model is patient-centered and physician led, and provides care from the pre-procedure assessment through the acute care episode, and recovery and post-acute care.

This process is in alignment with the goals of the proposed program of providing care from the pre-operative stage through survivorship (American Society of Anesthesiologists Gentile, 2017). The Peri-Operative Home Model was determined to fit the proposed program's goals of ensuring consistency of care and commonality of the provision of care from one discipline to the next ensuring that needed services were ordered by the physician and provided for the survivor (American Society of Anesthesiologists, 2014).

The Peri-Operative Surgical Home Model aligns with the Occupational Therapy Practice Framework (American Occupational Therapy Association 2014) through the service delivery model of providing direct client services in the hospital and outpatient settings (American Occupational Therapy Association, 2014). In addition, the model was utilized because it is patient-centered, physician-led, and interdisciplinary team-based approach, which aligns with the goals of the proposed program (American Society of Anesthesiologists, 2014; Gentile, 2017).

In order to guide the occupational therapy intervention, it was vital to have an occupational therapy specific model. Of importance was use of a model that is survivor-centered and considers the environment and context of the survivor along with the goals important to each survivor. The ultimate goal of the proposed program is to decrease risk of co-morbidities and promote quality of life throughout survivorship. As quality of life is defined differently for every survivor, the program must be individualized to focus on the desired roles and occupations important to each survivor.

The Person-Environment-Occupation-Performance Model fits the goals of the program ensuring the survivor (person) is the key factor and the focus at each stage. This

concept is partnered with what the survivor wants to do (occupations) which is gathered during the occupational profile, considered within their environment (facing their previous environments such as home, work, church now as a survivor) in order to create achievable goals (performance) (Christiansen, et al., 2015). The Person-Environment-Occupation-Performance Model blends well with the Empowerment Model as it keeps the survivor at the center of all care, assisting to empower each survivor with more individualized care throughout the proposed program's process.

This occupational therapy model furthermore, blends with the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2014) as the framework outlines the domain of occupational therapy to include: occupations, client factors, performance skills, performance patterns, and contexts and environments (American Occupational Therapy Association, 2014). The blending of this model with the practice framework is evidenced in the proposed program as the survivor receives one on one, individualized care from the occupational therapy practitioner. The program is designed to be protocol initiated; however, the care is individualized, focusing on the survivor and their goals. The survivor goals or desired occupations are determined through the completion of the occupational profile embedded into each occupational therapy evaluation. The person and their occupations are addressed in the proposed program through the occupational profile when the evaluating occupational therapist works with the survivor to determine their current physiological, psychological, neurobehavioral, cognitive, and spiritual factors. Additionally, the occupational profile includes assessing what the survivor wants or needs to be able to do in their daily lives and evaluates their current performance with these occupations and the context in which

they occur. Performance of these occupations is constantly assessed and addressed via individualized intervention approaches throughout the treatment process (Christiansen et al., 2015).

The integration of the theories and models to support the survivor and the program was integral to the creation of the program and its long-term success. It was imperative to ensure that the theories and models supported the program to be survivor-centered along with supporting the goals of education for prevention. Central to the entire program is the Person-Environment-Occupation-Performance model as the anchor for the proposed comprehensive occupational therapy program. This model puts the survivor and their needs at the center of all program activities. This model also supports that the survivors chosen occupations, the environments in which they interact, and their performance with those occupations in those environments, are key to survivor success. With this strong survivor-centered foundation, the Adult Learning Theory and the Empowerment Model were added for their ability to provide survivor benefit. The Adult Learning Theory ensures education provided to the survivor is appropriate in its form and delivery (while also utilizing the teach-back method); while the Empowerment model ensures the survivors understand the importance they play in understanding the education provided in order to improve their health. Lastly, because this program is part of a larger medical system, it was essential to have a healthcare delivery model that also ensured the program remained survivor-specific. The Peri-Operative Home Model assisted with the protocol design of the program. This model supported the protocol design of including a pre-operative, post-operative, outpatient, and long-term surveillance stage to ensure survivor needs are met from the time of diagnosis through long-term survivorship.

Parkview Regional Medical Center Stakeholder Meeting

A number of concerns emerged from the Parkview Regional Medical Center's stakeholder meeting. The most important concerns identified by the Senior Vice President, occupational and physical therapy practitioners, and nurses was the inconsistent and general lack of physician ordering of occupational therapy services for preventative, restorative, or wellness concerns, and the inconsistent provision of client education. Additionally, they reported that the education that was provided was not individualized to each survivor's specific needs. For example, survivors are Insgiven a handbook in the surgeon's office titled, *Breast Cancer Treatment Handbook* (R. Gonterman, personal communication, May 24, 2016). The handbook is very thorough; however, it is 242 pages, which runs the risk of being overwhelming to the survivors. The procedure of giving the handbook to survivors has been in place for approximately five years (R. Gonterman, personal communication, July 12, 2017). The Senior Vice President of the cancer institute reported that no one actually reviews the handbook with the survivor or points out the portions of the book that do or do not pertain to the survivor personally (R. Gonterman, personal communication, May 24, 2016). Because this handbook is so comprehensive, survivors have to decide and select on their own if particular chapters pertain to their unique situation.

An additional concern of Parkview Regional Medical Center's breast cancer team was that there is currently only one certified lymphedema therapist on staff, and this therapist only works in outpatient services. Lack of available and trained occupational therapy practitioners resulted in survivors being delayed in receiving care (R. Gonterman, personal communication, May 24, 2016). Additionally, supplies for lymphedema

treatment are not provided in occupational therapy and not available for purchase at Parkview Regional Medical Center, which results in a significant delay in initiating care for the survivors with lymphedema needs (R. Gonterman, personal communication, May 24, 2016).

Lastly, Parkview Regional Medical Center has very little space to accommodate breast cancer survivors during inpatient and outpatient treatment sessions. Plans were already in place to create private and semi-private chemo infusion areas, a more pleasant color palette to stimulate relaxation versus a clinical or sterile environment, and a dedicated space for oncology therapy services in an effort to support a more healing environment for patients, families, and staff (Huisman, Morales, van Hoof, 2012; R. Gonterman, personal communication, May 24, 2016). In addition, the hospital is prepared administratively and financially to hire and train occupational therapy practitioners for the breast cancer program (Gonterman, personal communication, May 24, 2016).

Expert Interview Recommendations

The experts interviewed from M.D. Anderson, and Florida Hospital, all spoke of the need for a protocol-driven program. They believed it must be automated to improve consistency of care between survivors and between physicians. They spoke to the fact that physicians often neglected to order services not because they do not value occupational therapy, but that they simply “forget.” This very important aspect of creating a successful program became the first step for implementation of the program. Runowicz et al., (2016) reported on the lack of continuity of care between the oncologists and/or surgeons and the survivor’s primary care physician. They explained that the areas

of responsibility throughout survivorship become blurred when it is unclear which healthcare specialist is responsible for ongoing cancer care. Thus, having a protocol-driven occupational therapy program will ensure services are consistent. This is achieved by the determination of roles and responsibilities of the healthcare team. For example, the surgeon initiates the protocol by the routine ordering of occupational therapy services at set intervals in the survivor's treatment journey and the occupational therapy practitioner follows a set protocol for the initiation of their services.

Additionally, experts also agree that the program must be individualized or survivor-centered, as no two survivors will have the same experience. Therefore, the ordering of occupational therapy will be the only aspect of occupational therapy services that is the same for all survivors. From that point forward, care is survivor-centered and individualized.

Insights from Residency Experience

Florida Hospital's Cancer Institute continues to expand and improve upon its cancer services, particularly in the area of patient care coordination. As Florida Hospital's Cancer Institute has grown and expanded, not only in the main hospital but also throughout the community, they are working to assure that the care provided to individuals with breast cancer and survivors is survivor-centered and a seamless process from diagnosis and throughout the survivors' life span (H. Roorda, personal communication, September 14, 2016).

Florida Hospital's Cancer Institute Associate Director of Cancer Services acknowledged that there is always room to improve not only with consistent care but also particularly in the area of prevention of cancer-related co-morbidities and survivorship

care (H. Roorda, personal communication, September 14, 2016). This concern regarding consistency of care was also supported by the literature review. Runowicz et al., (2015) reviewed 1,073 articles that met inclusion criteria and included 237 articles as their evidence base. Runowicz et al., (2015) provided guidelines for the provision of consistent care through preventative measures along with consistent care during the active treatment intervention and throughout life-long survivorship. The researchers' guidelines include counseling survivors about the importance of maintaining a healthy lifestyle, monitoring for post-treatment symptoms that can unfavorably affect quality of life, and monitoring for adherence to long-term therapy recommendations (Runowicz et al., 2015).

Often the ancillary or support services can make all the difference for survivors battling cancer; if the support services aren't provided to address secondary complications like lymphedema, it won't matter so much how good the medical treatment is because the patient then lives with potentially chronic conditions such as lymphedema as a daily reminder of having had breast cancer (H. Roorda, personal communication, September 14, 2016).

Florida Hospital's Cancer Institute ancillary staff includes nurses with specialization in cancer care, nurse navigators, educational services, genetic health services, the cancer registry, therapy services, infusion center, and the mammography centers. Given so many stakeholders and the fact that they are located on various campuses, survivor care coordination is a challenge, particularly in the areas of prevention, management, and survivorship (H. Roorda, personal communication, September 14, 2016; Runowicz et al., 2015). The experts at Florida Hospital said they

are striving to achieve a protocol driven program that includes all the breast cancer support services at all of their locations providing breast cancer care. They noted that once the survivor is deemed cancer-free they seem to fall out of the program. Their recommendation was having surveillance throughout survivorship and that it has to be protocol driven and discipline specific in order to be successful with so many factors like the mentioned various locations and numerous health care providers participating in the survivors' care.

Residency at Florida Hospital's Cancer Institute provided an opportunity to learn how a larger cancer center is providing care along with areas in which it plans to expand and improve upon. In order for Florida Hospital to provide services to meet the recommended guidelines, services that are more comprehensive will be required. In alignment with best practice and the top five cancer centers studied in the literature review, Florida Hospital's Cancer Institute provides the following services:

- animal-assisted therapy
- lymphedema program
- bra prosthetics and fittings
- cosmetology/wig boutique
- distress screening
- sleep clinic
- financial counseling
- genetics counseling
- breast cancer specific gift shop
- infertility clinic

- nutrition services
- pain management
- spiritual and psychological support
- smoking cessation
- support groups on-site
- survivor resource library (Florida Hospital, 2017).

At Florida Hospital, many of the breast cancer-specific services are provided within the Eden Spa center. There, survivors can visit the gift shop, which provides many breast cancer-related gifts and jewelry, along with cosmetics designed specifically for individuals going through cancer treatments. This spa also provides full lymphedema services, a prosthetic clinic, manicure and pedicure salon, hair and wig salon, and massage services, all conveniently located in one center (Florida Hospital, 2017).

In order for Florida Hospital to align with the top five cancer centers previously reviewed, the following services are recommended:

- Bioimpedance spectroscopy
- Body image consulting
- Bone/musculoskeletal health program
- Mobile patient app
- Caring for the caregiver program
- Prosthetic donation center
- Daycare
- Exercise physiologist
- Memory garden

- Metabolic testing/weight management program
- Nutrition services/cooking classes
- Cognitive support services
- Complementary and alternative medicine clinic
- Recreational therapy including: music/art/writing
- Return to work program
- Web-based support groups
- Survivor volunteer program

The residency experience added great breadth and depth to understanding the components of a comprehensive program. The report that Florida Hospital has difficulty getting consistent occupational therapy services ordered by physicians confirmed the need for the proposed program to include a protocol driven, physician order-set within the electronic medical record (H. Roorda, personal communication, September 14, 2016).

Insights from the International Cancer Summit

The information obtained from the summit was helpful in order to understand the inconsistency in the provision of client-centered rehabilitation services across the country and abroad. Insights gained from the International Cancer Summit all revolve around the best practice in cancer rehabilitation stemming from a protocol-driven program.

Additionally, the experts spoke to the importance of the protocol being initiated at the time of diagnosis and that it involve a comprehensive rehabilitation team that includes occupational therapy. This protocol-driven model supports best practice by improving consistency in care and services provided. Lastly, using a protocol-driven cancer

rehabilitation program, many potential co-morbidities may be prevented or detected earlier, therefore supporting improved patient outcomes.

Survivorship was addressed often at the Summit and the importance of providing care throughout a survivor's lifetime. Historically, medical providers had the goal of curing the individual's cancer and keeping the individual alive and therefore the medical plan of care was very short-term in nature. Due to many medical advances in surgical techniques along with advances in chemo and radiation therapies, women are surviving breast cancer and therefore a shift has occurred into looking at the long-term needs of the survivors (N. Stout, personal communication, October 6, 2017). The expectation is now that the individual will survive and therefore health care practitioners must consider how having had breast cancer may cause physical, mental, and emotional challenges both during the time of treatment and throughout the life of the individual as they age (N. Stout, personal communication, October 6, 2017).

Some specific areas of survivor concern that the International Cancer Summit addressed include the following: neuromuscular conditions such as peripheral neuropathy; musculoskeletal conditions such as frozen shoulder; pain; fatigue; and cognitive changes. Notable is that these conditions can have varying onsets from initial diagnosis throughout survivorship. These ongoing needs speak to the importance of continued survivor surveillance in a comprehensive breast cancer rehabilitation program.

Historically, the medical field has not considered that survivors must return to their previous roles in life including returning to basic daily living, returning to work, caring for children and others, etc. This area of survivor need provides occupational therapy the opportunity to help return survivors to prior life roles through remediation,

helping them adjust their environments to return to previous roles, or potentially the opportunity to acquire new roles (N. Stout, personal communication, October 6, 2017).

During the summit, there was an opportunity to speak with Select Medical's national medical director about the inclusion of occupational therapy services into breast cancer programs. The director was quick to agree that occupational therapy should be included in breast cancer programs. He further stated that as a physiatrist and medical director, he has personally seen the benefits of occupational therapy to improving a survivor's quality of life and agreed that the program needs to be physician-protocol driven to ensure that occupational therapy is ordered for every breast cancer survivor to begin in the pre-operative stage and continue throughout survivorship (M. Stubblefield, personal communication, November 11, 2016).

Insights from Continuing Education

The information obtained from the literacy course provided insights into the design and development of the comprehensive breast cancer program to ensure all survivors literacy needs were taken into consideration in the selection of education material. Friedman and Hoffman-Goetz (2008) studied health literacy in cancer care. They concluded that definitions of literacy and health literacy are not being used consistently in the cancer education literature and that best practice definitions of literacy and health literacy are important, especially when screening individuals for their understanding of cancer prevention and treatment information. The health literacy needs of the survivors were taken into consideration in development of the proposed program using handouts that promote ease of understanding and provide a pictorial explanation as well. This enables each survivor to verbally hear the instructions from the occupational

therapy practitioner, see the practitioner physically demonstrate the activity, read the information on the handout and follow pictorial diagrams on the handout as well. The survivors, additionally, will return demonstrate the activity and the occupational therapy practitioner will provide constructive feedback to ensure the survivor comprehends the information, thus using the teach-back method.

The continuing education courses provided occupational therapy specific guidelines for the provision of a comprehensive breast cancer program. The education gathered from the sources supports that occupational therapy practitioners have a clear role in the areas of cancer physical and cognitive/psychosocial rehabilitation, cancer-related fatigue, and lymphedema.

Themes from Cancer Survivor Focus Group

The focus group met on February 21, 2016, at Parkview Regional Medical Center in the cancer institute's lobby and was conducted by the primary investigator. The focus group was completed at the close of the survivors' monthly support group. Participants had all received cancer care from Parkview Regional Medical Center and were currently finished with all surgical and medical procedures and deemed cancer-free. All survivors were at various stages in their survivorship. Eight participants met all inclusion criteria. It is notable that none of the participants received occupational therapy services throughout their survivorship. The primary investigator maintains notes from the focus group in a locked cabinet.

The focus group had originally been advertised in Parkview Regional Medical Center's Cancer Center with no interest noted. The director of the cancer center spoke with the leader of the breast cancer support group and it was arranged that the primary

investigator would come to the support group and see if participants desired to participate in a focus group immediately after their scheduled monthly support meeting. The focus group questions (Appendix D) were aimed at discovering if education was provided to the survivor pre-operatively, while in the hospital after surgery, and ongoing throughout their survivorship. Additional questions focused on the education they received on lymphedema prevention and who provided it, along with who provided the best care overall. An open-ended question was asked regarding the aspects of care they believe could be improved upon.

The majority of participants focused on the individual care or lack of individual care received, based on their perceptions and experiences. The education they received varied greatly from some receiving no education to some receiving verbal education, and lastly, some receiving both verbal and written education. Lymphedema education provided to the survivors was inconsistent as well, ranging from no education, to education provided by the physician or the physical therapist, and to individual survivor internet searches. One survivor stated the following when asked about education that was provided to her in the hospital, “No, they left a bra on my table, but that was it, they really only focused on the pain level.” Another survivor stated that she had had two to three episodes of cellulitis and that her surgeon did not know what to do with her. She stated that she searched for information (internet) and found the Lymphedema Association of North America website. The information provided to her on the website prompted her to consult with her physician about the possibility of having lymphedema. Unfortunately, this is an example of not providing preventative information and therefore it potentially resulted in having to treat co-morbidities retrospectively.

Many survivors reiterated that they wanted more one on one time with practitioners, improved consistency of care such as the verbal and handout information on exercises and lymphedema precautions provided by their healthcare practitioners, and to receive more preventative and wellness information after being considered cancer-free. The survivors expressed that when a fellow survivor they knew in support group received education on a topic that they had not, they felt like they were missing something, and that not knowing could put them at risk of additional problems. Members of the focus group all agreed that the handbook received from the cancer institute was overwhelming and therefore they did not use it as much as they believe they could have. One survivor stated, “Ensure survivors are told what to expect throughout the entire process, not just surgery.”

Participants compared the care they received with some of the larger cancer centers and many said that they liked the idea of having additional services such as a spa and workout facility, but that they do not want to have those options located at the hospital. They all agreed that they had spent enough time at the hospital and would not choose to go back to the hospital for wellness services. One participant said that she would participate in such wellness activities if she could afford it and if it were close to her home like the local YMCA. The literature supports the implementation of early activity and long-term exercise programs therefore the proposed program recommends satellite breast cancer exercise programs at local YMCAs in order to better serve the needs of the survivors. It is recommended that Parkview Regional Medical Center work with the local YMCAs to create breast cancer-specific programs that can be carried out by the exercise specialists at the YMCAs. This ensures a breast cancer-specific exercise

program and provides for the survivor to attend in their local community versus returning to the hospital for services.

Because survivors wish to have spa services but they do not wish to return to the hospital for them, the proposed program recommends a spa referral program. It is recommended that Parkview Regional Medical Center work with local spa centers in the area to ensure the survivors needs can safely be met through the spa center's services. Once a relationship is established, Parkview Regional Medical Center will have a list of recommended spa centers to provide to their survivors based on their preferred geographical location.

Two participants discussed that they would rather see more money put into the ongoing and advanced training of the oncology health care practitioners instead. They spoke of how they did not feel that the health care practitioners understood what they were experiencing and that they did not have the ability to treat them like individuals and adjust the care provided accordingly. One participant gave the example of an oncology nurse stating, "That's normal" in response to radiation burns on her breast. The participant found that statement offensive and stated, "nothing is normal about having breast cancer." The proposed program recommends that Parkview Regional Medical Center provide annual oncology team member screening and education on empathy and caregiver fatigue and physical and mental burnout screening. This will enable the hospital to monitor employees who may be at risk for burn-out and fatigue and provide them the needed assistance early on.

One individual felt that she needs more supportive care now (in survivorship), then in all previous stages of having cancer. She explained that there seems to come a

day when all the medical support goes away and you are expected to resume life as prior, but that nothing is as it used to be. One survivor stated, “No one ever talked to me about getting back to my normal life and what that would be like.” The occupational therapy portion of the proposed program addresses these concerns through the provision of occupational therapy, which provides for the physical, cognitive, and emotional needs of the survivors. In the proposed program, the occupational therapy practitioner works with the survivor from the initial diagnosis, throughout their active medical care, and with an annual email follow-up throughout their survivor lifespan. Occupational therapy addresses the return to previous roles and occupations from a physical and psychological standpoint. Once the survivor is discharged from occupational therapy, they will be contacted annually for a check of their status and to determine if occupational therapy is warranted at that time.

The focus group participants acknowledge that support groups (Conquering Breast Cancer, Look Good, Feel Better and a Lymphedema Support Group) and smoking cessation classes for survivors are available at Parkview Regional Medical Center, but they pointed out that survivors typically only attend these groups after many weeks or months into their cancer journey. They explained that they assumed that the support group was for individuals who are finished with medical care or that they felt they already had so many appointments and that they were simply too busy to add another commitment. Support groups for the family/friends/caregivers of survivors do not exist at this time nor do online based support groups (R. Gonterman, personal communication, May 24, 2016) despite the potential for survivor success. The proposed program recommends that the oncology nurse navigators provide information and education on the

support groups at the start of care and explain that the support groups are for their entire journey, not only after medical care has ended. Additionally, the proposed program recommends an on-line professional led support group for those survivors who prefer the online format to the face-to-face format.

The participants of the focus group confirmed that there are many inconsistencies in the provision of breast cancer care, even for individuals who received care at the same facility and often with the same physicians and other health care providers. It became clear that there are inconsistencies in the areas of education provided, when that information is provided, and in the ordering of occupational therapy services. This has been addressed through the proposed program via a protocol driven comprehensive occupational therapy program that initiates care at the first surgical visit and continues with annual surveillance throughout the survivor's life.

In summary, survivors want information as soon as possible and they want it to be consistent from provider to provider, which is also supported by Binkley et al., (2012). They do not want to hear that someone in their support group got something that they did not (such as education on lymphedema), as they felt that these inconsistencies led to fear. They want individualized care that is tailored to their specific needs and they want this care to extend to "life after breast cancer" (throughout survivorship).

Parkview Regional Medical Center's Proposed Comprehensive Occupational Therapy Program

This proposed comprehensive occupation therapy program is centered on improving care provided to breast cancer survivors through participation in a protocol driven occupational therapy program aimed at preventing or decreasing the severity of

co-morbidities. The program focuses on prevention of cancer treatment-related functional deficits and comorbidities, remediation of functional impairments, and surveillance throughout the survivor's lifespan. An occupational therapy practitioner sees survivors in Stages 1-3 with Stage 4 consisting of annual surveillance via an email. During Stage 1, the survivor is seen pre-operatively before having her mastectomy. In Stage 2, the survivor is seen post-operatively while still in the hospital, prior to discharge. In Stage 3 the survivor is seen one month post-operatively in the outpatient rehabilitation setting for four total visits at the following intervals: one month post-operatively, then at three months, six months and one year for functional assessment and follow-up. Stage 4 continues annually over the lifespan of the survivor through annual electronic email contact for ongoing surveillance of potential needs.

In order to provide an understanding of the resources needed to actualize the program (inputs), the activities that will take place (objective), and purpose (outputs) of each activity, and the results the program hopes to achieve (outcomes), a logic model was created (McDavid, Huse, & Ingleson, 2012). Lastly, the sustaining goals of improving care (impact) are provided below.

Table 4

Comprehensive Occupational Therapy Breast Cancer Program Logic Model

Inputs	Objectives (1-3) for this Project	Outputs	Outcomes	Impact
<p>Parkview Regional Medical Center's upper level administration/ leadership/ financial support.</p> <p>Parkview Regional Medical Center's breast cancer care team and ancillary staff support/leadership/ training, physical space/materials.</p>	<p>1. Identify the components of a comprehensive occupational therapy breast cancer care program.</p> <p>2. Develop a comprehensive occupational therapy evaluation and intervention protocol.</p> <p>3. Develop program evaluations to measure both program and survivor-outcomes.</p>	<p>Provides evidenced-based/best-practice information for creation of the program.</p> <p>Provides comprehensive and consistent care across physicians and occupational therapy.</p> <p>Provides the needed evidenced based/best practice guidelines for implementation of the program.</p> <p>Provides Parkview Regional Medical Center with a means to evaluate the program at the program and survivor level.</p> <p>Provides long-term program outcomes measures for long-term data tracking.</p>	<p>Increased survivor satisfaction with their care.</p> <p>Decreased risk of co-morbidities.</p> <p>Continued survivor surveillance throughout their lifespan.</p> <p>Positive survivor lifestyle change.</p>	<p>Improved care through consistency of services provided to breast cancer survivors throughout the survivor's lifespan.</p> <p>Survivor reported lifestyle changes for improved health throughout survivorship.</p>

Once objectives one through three (Table 4) have been met, i.e., the program has been developed and implemented at Parkview Regional Medical Center, program evaluation will begin and occur yearly at the responsibility of the Senior Vice President of the Cancer Institute. Participants included in the program evaluation will be all individuals diagnosed with breast cancer at Parkview Regional Medical Center who will have mastectomy surgery. Participants, who do not participate in the protocol, will complete the BREAST-Q at their one-year surgical visit follow-up to allow for comparison between the two groups.

Occupational Therapy Breast Cancer Protocol

In preparation for initiation of the occupational therapy breast cancer protocol, some recommendations include the following:

- Identify one additional therapy staff member to support the cancer rehab program.
- Procure training and establish clinical integration of this individual into the cancer center with patient interface per the program protocol.
- Identify and create space for a consultation area (clinical assessment, testing, screening and educational interventions) for an occupational therapist to be in the infusion center.
- Identify and create a private space for a treatment area (outpatient occupational therapy intervention) within the current outpatient department.
- Improve awareness of medical and support staff (includes nurses, nurse navigators, and techs) to the functional needs and benefits of rehabilitation by conducting quarterly grand rounds lectures to hematology, oncology, and radiation oncology for rehabilitation-based topics in order to keep them up-to-date

on the successes of the program, new rehabilitation innovations, and current research in rehabilitation and breast cancer.

- Create a web-based library with videos for education of staff in remote locations. Develop a repository of articles that supports cancer rehabilitation interventions and models of care that they can access and use for self-directed learning.

The Occupational Therapy Breast Cancer Protocol is a 4-Stage protocol that is initiated at the first survivor visit with the breast surgeon. The protocol was developed using a client-centered approach in that at Stages 1-3 of the protocol, the survivor is evaluated and an occupational profile is completed in accordance with the Occupational Therapy Practice Framework (American Occupational Therapy Association 2014). The Adult Learning Theory and the Empowerment Model were incorporated throughout the program as evidenced by the educational opportunities at each stage utilizing the teach back method for learning. The education provided is designed to increase the survivor's control over their own medical situation from the start of treatment throughout their survivorship.

The results of the literature review, meeting with Parkview Regional Medical Center's stakeholders, experts interviewed, on-site residency, attendance at the International Cancer Rehabilitation Summit, continuing education, and completion of a breast cancer survivor focus group, all spoke to the importance of ensuring the program is automated and protocol driven for the ordering of occupational therapy, consistency in care, and preventing delays in receiving care. The information learned through this process indicated that occupational therapy services are not consistently ordered for survivors and that it must be an automated process versus leaving the ordering up to each

individual breast surgeon and potentially delaying care. Additionally, the stakeholders spoke to the importance of including prevention of potential co-morbidities, which is why education is provided at each stage of the protocol. Lack of individualized care was another strong theme among focus group participants; therefore, the proposed program has the survivor being seen one on one by an occupational therapy practitioner to ensure each session remains client-focused and individualized. Being seen one on one is supported through the Adult Learning Theory by providing the learner the opportunity to learn by observation and example. Additionally, the focus group members spoke of not receiving individualized education. Despite the protocol containing pre-determined education, the occupational therapist will use their clinical reasoning skills to individualize each occupational therapy session, as needed, for the survivor. The on-site residency demonstrated the need to ensure that the hospital remains in touch with survivors over their lifespan or survivorship. Therefore, in Stage 4, the occupational therapy department will make automated contact with survivors yearly for ongoing surveillance.

Noted in the design of the protocol are educational opportunities at each stage. The topics covered in the protocol's education were chosen based on information from continuing education, the breast cancer survivor guidelines from the American Cancer Society, and the American Society of Clinical Oncology. These organizations provide a very detailed listing of concerns to be addressed with survivors (Runowicz et al., 2016). The capstone author pulled from this list of concerns, areas that are within the scope of practice for occupational therapy practitioners and included those in the proposed program.

Keeping the educational aspects survivor-centered also involved ensuring the survivors' health literacy abilities were considered throughout the design. Each occupational therapy evaluation that is completed in Stages 1-3 include an assessment of the literacy abilities of the survivor. Additionally, all educational materials were chosen for the ease of readability and comprehension of survivors.

The value of support to the survivor's caregivers and family, along with the value of an on-line support group was evident in the literature and in review of the top cancer centers. Parkview Regional Medical Center does not offer family and caregiver support groups or online support groups. The proposed program will not address this concern, but is a recommendation to the Senior Vice President of the cancer program to have both aspects implemented into their program.

Use of the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2014) is evidenced throughout the proposed program with the process of occupational therapy incorporating an evaluation, which includes an occupational profile and focuses on client-centered intervention and goals. Client factors are taken into account in the proposed program using the occupational therapy evaluation, occupational profile, and protocol and survivor-specific education. Additionally, the proposed program has included individual survivor outcome measures specifically addressing survivor beliefs and spirituality along with their body functions and structures. The proposed program consistently addresses the survivor's performance skills (motor, process, and social) through the occupational therapy evaluation and treatment if further treatment is warranted in Stage 4. Survivor performance patterns (habits, routines, rituals, and roles) and contexts and environment are woven through the

program as the occupational therapist addresses this through the evaluation and is continually assessing during intervention and updating goals as necessary.

Therapeutic use of self and clinical reasoning are naturally embedded in the program as the therapist completes the evaluation and intervention process. The domains of occupational therapy (occupation, client factors, performance skills, performance patterns, and context and environment) are woven throughout the proposed program through individualization of services. The survivors' valued and necessary occupations are determined by the survivor and their level of performance with those occupations is determined by the therapist during each evaluation in Stages 1-3.

The following diagram provides details of the comprehensive occupational therapy four-stage protocol, including when occupational therapy is ordered, when evaluations are completed, and the education provided in each stage.

4-Stage Occupational Therapy Breast Cancer Protocol

1

•Pre-Operative Stage 1

- Surgeon orders mandatory (must be completed before surgery) occupational therapy pre-operative breast cancer evaluation and treatment
- Patient is seen pre-operatively as an outpatient by the occupational therapist with the following being completed during this evaluation and treatment session:
 - Occupational Therapy Breast Cancer Pre-Operative Evaluation (Appendix C)
 - BREAST-Q Mastectomy Module Preoperative Survey (Appendix D)
 - Education/Treatment:
 - Prevention and Control of Upper Extremity Lymphedema (Appendix G)
 - Deep Breathing (Appendix E)

2

•Post-Operative Stage 2

- Surgeon orders inpatient occupational therapy evaluation and treatment prior to discharge.
- Surgeon orders outpatient occupational therapy evaluation and treatment, one month post-op to be scheduled before inpatient discharge.
- Patient is seen as an inpatient by the occupational therapist with the following being completed during this evaluation and treatment session:
 - Occupational Therapy Breast Cancer Post-Operative Evaluation (Appendix F)
 - Education/treatment:
 - Mastectomy Exercises (Appendix H)

3

•Outpatient Stage 3

- Patient is seen as an outpatient by the occupational therapist at one, three, six, and 12 months post-operatively. The following being completed during this evaluation and treatment. Note: If indicated ongoing treatment will be provided.
- Occupational Therapy Breast Cancer Post-Operative Outpatient Evaluation (Appendix I)
- Occupational Therapy Breast Cancer Post-Operative Outpatient Lymphedema Evaluation (if diagnosis has been confirmed) (Appendix J)
- BREAST-Q Mastectomy Module Postoperative Survey (Appendix K)
- Treatment: As indicated
- Education
 - Stress Management and Relaxation Techniques (Appendix L)
 - Mastectomy Exercises (Appendix M)
 - Measuring Your Arm Following Mastectomy (Appendix N)
 - Energy Conservation (Appendix O)
 - Good Posture (Appendix P)

4

•Survivor Surveillance Stage 4

- Survivors are followed on a yearly surveillance program via MyChart email (Appendix Q)

1. a Pre-Operative Stage 1

In response to input from experts and the focus group participants, the first step in the program is completed by the survivor's surgeon. This step involves the surgeon entering an "occupational therapy evaluation and treatment per breast cancer protocol" order into the electronic medical record. This is completed at the time the surgeon meets with the survivor for consultation and scheduling of surgery. At this same time, the surgeon explains to the survivor, that the pre-operative occupational therapy evaluation and treatment is mandatory prior to having surgery. This occupational therapy order is received electronically by the rehabilitation department. The rehabilitation scheduler then calls the survivor to schedule an outpatient occupational therapy evaluation to take place in the outpatient occupational therapy area of the cancer institute.

During the first occupational therapist/survivor interface, the occupational therapist will complete the Occupational Therapy Breast Cancer Pre-Operative Evaluation (Appendix E). A one-hour time slot will be provided for the completion of this first visit. The occupational therapy evaluation has been created with the Occupational Therapy Practice Framework's occupational profile as the foundation to guide the evaluation and treatment process (American Occupational Therapy Association, 2014). The occupational therapy evaluations completed in Stages 1-3 have been selected in accordance with the Person-Environment-Occupation-Performance model to ensure that the survivor is the central focus and that the survivor's goals will guide the plan of care, despite the program being designed as a protocol.

The purpose of this evaluation is to gather baseline subjective and objective data regarding the survivors' medical and surgical history and concerns they may have about

surgery. The survivor's baseline functioning in activities of daily living and instrumental activities of daily living will be obtained. Baseline pictures of the bilateral upper extremities can also be taken, providing the consent to photograph release form is completed by the survivor and therapist. This information provides a baseline from which the occupational therapy practitioner and survivor can set future treatment goals if further treatment is indicated. Having baseline measurements such as bilateral upper extremity circumferential measurements enables the occupational therapist to track the survivor's circumference post-operatively during their outpatient visit. This ability to compare baseline to after surgery allows for early detection of co-morbidities such as sub-clinical lymphedema and adhesive capsulitis.

Additionally, the information gathered from this pre-operative session allows the occupational therapy practitioner to determine if there are current functional limitations that exist, establish survivor goals and provides the opportunity for the practitioner to answer any questions and address any concerns or fears the survivor may have at this point in their journey regarding their functional status.

The occupational therapist will also have the survivor complete the BREAST-Q Mastectomy Module (Pre-Operative) 1.0 (Appendix F). This module additionally provides baseline data on areas such as body image, emotional health, physical dysfunction, pain, and sexual health, which can be used for comparison in subsequent visits to assist the practitioner in determining if a functional deficit exists post-surgery. In addition, success of the comprehensive breast cancer program will be assessed via the BREAST-Q. The BREAST-Q is a patient-reported outcome instrument designed to assess outcomes among women undergoing different types of breast surgery. All

survivors will complete the BREAST-Q at their first pre-operative appointment and then complete it again at six months' post surgery and again at one-year and then yearly intervals via MyChart emails. This instrument will provide data on any complications the survivors are facing and indicate whether these complications were improved through the comprehensive breast cancer program treatments. This tool can also screen for potential new concerns that may warrant intervention as well. Additionally, the BREAST-Q provides questions at the end of the post-operative form on satisfaction with medical team members, with the exception of the surgeon.

The instrument is founded on the domains of patient satisfaction and health-related quality of life. Contained in each of these domains, are six subthemes (quality of life; physical, psychosocial, and sexual wellbeing; patient satisfaction; satisfaction with breasts; satisfaction with the overall outcome; and satisfaction with care. The BREAST-Q assesses patient factors, such as body image, pain, sleep, and sexual health both preoperatively and post-operatively, providing quantifiable data for comparison (Memorial Sloan-Kettering Cancer Center, 2012).

The BREAST-Q is designed to provide health care practitioners and researchers with the capability to adapt the instrument to their specific needs. This means the instrument can be adapted to fit the comprehensive needs of the cancer center as well as their survivors. The same data will be gathered on every breast cancer survivor going through the comprehensive program at Parkview Regional Medical Center. The BREAST-Q was chosen from other instruments because of its comprehensive ability to measure the program as a whole from start to throughout survivorship. It can be adapted to fit the desired program evaluation content and covers a wide range of areas that correlate with

the areas to be addressed by the comprehensive program. The BREAST-Q was developed using psychometric methods and input from over 2000 patients, has been validated in over 15,000 patients, is highly reliable, valid, and responsive. Additionally, the BREAST-Q is easy to read, comprehend, and complete for the survivor.

The pre-operative Stage 1 ends with the occupational therapist providing handouts and education on Prevention and Control of Upper Extremity Lymphedema (Appendix G) and education and completion of deep breathing exercises (Appendix H). The prevention of lymphedema handout is designed to educate the survivor on what lymphedema is, how to recognize the early signs of lymphedema, and how to protect the arm from injury, infection, and possibly the onset of lymphedema (Merchant & Chen, 2015).

For the deep breathing exercises, the therapist will utilize the teach-back method, providing demonstration of the exercises; have the survivor return the demonstration, and then the therapist will provide the survivor with constructive feedback. Deep breathing exercise should be initiated prior to surgery so the survivor can practice the technique and become comfortable with completing it. Post-surgery, the importance of completing deep breathing exercises to decrease risk of pneumonia, encourages the survivor to get out of bed and sit in a chair, encourages expansion of the chest allowing the muscles (particularly around the surgical site) to stretch, and encourages proper posture. Additionally, completing the breathing exercises aims to decrease stress, decrease pain, and increase relaxation and improve overall quality of life (Dhillon et al., 2009). The importance of completing the exercise, when to complete, and how often to complete, will be determined by the clinical expertise of the occupational therapist, individualizing the care to the specific survivor.

2. b Post-Operative Stage 2

Stage 2 of the occupational therapy breast cancer protocol is initiated by the surgeon with the entering of the “occupational therapy evaluation and treatment prior to discharge-per breast cancer protocol” order in the electronic medical record. This order will be electronically received by the occupational therapy department and the evaluation and treatment will be completed prior to the survivor being discharged from the hospital. Additionally, at this same time, the surgeon will input an “outpatient occupational therapy evaluation and treatment-per breast cancer protocol at one, three, six, and 12 months postoperatively.” This appointment is made prior to the survivor being discharged from the acute care setting by the social worker.

The occupational therapist uses the occupational therapy breast cancer post-operative evaluation (Appendix I) and the time this process takes is estimated to be 45 minutes, but variable to meet survivor needs. This evaluation will gather similar information as the pre-operative evaluation in order to determine post-surgical needs and/or concerns. The occupational therapist provides the handout on mastectomy exercises to the survivor (Appendix J). Again, the therapist demonstrates each exercise, the survivor returns the demonstration, and the therapist provides feedback as needed. These exercises are designed to maintain and/or regain prior range of motion in the survivors’ cervical, shoulder, back, and chest regions. It is not uncommon for survivors after surgery to assume a forward shoulder/kyphotic position of comfort. However, it is important to maintain muscle length for range of motion, prevention of scarring of the tissues, and to allow the chest cavity the range of motion for deep breathing (Merchant & Chen, 2015).

2. c Outpatient Stage 3

The third stage of the comprehensive occupational therapy breast cancer protocol begins with completion of the occupational therapy breast cancer post-operative outpatient evaluation (Appendix K) with a 90-minute time slot provided for completion of the protocol. This first visit is at four weeks post-operative. Based on functional assessment, survivors will fall into one of two categories of need for rehabilitation services in stage 3: 1) no existing functional deficit; requiring only education and will continue with the sequenced follow ups at three, six, and 12 months, 2) a functional deficit exists requiring intervention to alleviate or significantly improve a functional impairment or disability. The second category proceeds with full outpatient rehabilitation services being initiated (Stout et al., 2012).

Additionally, if the survivor's surgeon has diagnosed lymphedema by this point in the treatment continuum, then the occupational therapist will utilize the occupational therapy breast cancer post-operative outpatient lymphedema evaluation form (Appendix L). The difference in these two occupational therapy evaluation forms is that the lymphedema form contains all of the same information to be assessed as the occupational therapy outpatient form, however, includes areas that the occupational therapist will need to assess in order to provide lymphedema treatment. In addition, the survivor completes the BREAST-Q Mastectomy Module (Post-Operative) 2.0 form (Appendix M). The completion of these evaluations enables the therapist to identify changes from the baseline measurements and provide treatment if indicated.

Education completed in Stage 3 is provided using the handouts noted in Appendices N-R. Each of these educational handouts will be given to the survivor, with

the therapist utilizing the teach-back method to ensure comprehension. If the occupational therapist determines that further treatment is indicated in order for the survivor to gain independence with these recommendations, then that will be indicated on the evaluation's plan of care section and further occupational therapy treatment sessions will be scheduled.

The stress management material enables the survivor to understand what causes stress, how to identify her own personal causes of stress, to recognize how stress affects her individually, how to cope with stress, and how to provide self-care to handle her stress (Dhillon et al., 2009). The mastectomy exercises in Stage 3 are more advanced than the first set of exercises provided in Stage 2. These exercises are designed to stretch the chest wall musculature and lengthen soft tissues to enable proper posture and range of motion of the shoulder in all planes. The exercises include use of a dowel bar or even a broom can be utilized to provide active assistance to keep the soft tissue lengthened (Merchant & Chen, 2015).

The survivor is educated on how to measure their arm in order to allow the survivor a means to track the girth of their arm on the same side as their mastectomy. By keeping periodic measurements, the survivor will be able to detect an increase in girth, which would prompt them to contact their physician for an examination to determine if they are experiencing lymphedema and if further occupational therapy is warranted (Fu et al., 2014).

Energy conservation education is provided to the survivor to assist them to learn techniques to pace and plan their activities accordingly, to decrease fatigue. Often with surgery and additional cancer treatments, survivors find that they are fatigued and have

difficulty completing activities of daily living; use of energy conservation techniques can assist with preventing and limiting this level of fatigue (Yuen & Mitcham, 2006).

Education is provided on good posture to minimize the stress to the survivor's spine from a natural tendency to take on a kyphotic posture after mastectomy surgery. Additionally, having good posture assists to keep the joints in best alignment for the best range of motion and mechanical advantage, which also assists to decrease or prevent fatigue during daily activities (Malicka, Barczyk, Hanuszkiewicz, Skolimowska, Wozniowski, 2010). In Stage 3 the occupational therapist determines if the survivor warrants further treatment, for example if the desired education was unable to be thoroughly or completely covered during the first evaluation and treatment.

The next step of stage 3 is seeing the patient for follow-up in the outpatient setting at 3, 6, and 12 months post-operatively. These visits allow the therapist to continue to monitor upper extremity girth and function. If a decline in any assessed area exists, then the survivor will be triaged into active outpatient treatment at the frequency discretion of the evaluating therapist.

2. d Survivor Surveillance Stage 4

Stage 4 is initiated one year post-operatively and then each year following as a means of remaining in touch with the survivor for ongoing surveillance. The emails will be automatically generated and sent to the survivor through their patient portal called "MyChart." The email contains a survey (Appendix S) asking the survivor five questions regarding their current health status. If the survivor answers "NO" for any questions 1-4, or "YES" for question 5, they will be asked if they would like a follow up email or

telephone call from their physician's office to discuss any breast cancer-related health concerns they may have.

Program Evaluation

Program evaluation ensures the program is achieving the goals it was designed to achieve. There are two sets of program evaluation goals with the first centered on survivor participation in the protocol and the second centering on comparison of BREAST-Q scores for the survivors that participated in the program versus those who did not.

The first set of goals will be geared toward working to increase survivors' participation in the protocol. It is anticipated at not all surgeons will initially require or mandate that their patients attend the pre-operative visit and subsequent protocol-sequenced visits. It is anticipated that over time, results will indicate that survivors who completed the protocol will demonstrate better scores on the BREAST-Q than those who did not participate in the protocol indicating a higher level of function, quality of life, and return to life roles. Through the grand-round meetings, surgeons can be updated on the comparison data in hopes that they will then mandate their patients participate in the program.

Program Evaluation: Participation

1. By the end of year one, the program will be capturing >50% of newly diagnosed breast cancer survivors receiving mastectomy surgery by completion of the protocol.

2. By the end of year three, the program will be capturing >80% of newly diagnosed breast cancer survivors receiving mastectomy surgery by completion of the protocol.
3. By the end of year five, the program will be capturing 100% of newly diagnosed breast cancer survivors receiving mastectomy surgery by completion of the protocol.

The second set of program evaluation goals utilizes the BREAST-Q to assess survivor outcomes. The BREAST-Q allows comparison of BREAST-Q scores between those who participated in the program and those who did not. This is achieved with survivors through their completion of the BREAST-Q at their pre-operative visit as a baseline measurement and at their one-year occupational therapy outpatient follow-up visit. Comparison is achieved with survivors who do not participate in the program through the completion of the BREAST-Q at their first surgical visit as a baseline measurement and at their one-year surgical follow-up visit.

The BREAST-Q scales for both preoperatively and postoperatively are linked psychometrically to measure change. Women may complete the pre-operative questionnaire at any time prior to surgery (baseline assessment) and the post-operative questionnaire at any time point after surgery (follow-up data).

Program Evaluation: Survivor Quality of Life

The scores outlined below were chosen for the physical wellbeing section based upon the patient scoring system one through five with five being the worse or more negative outcome. The scores were chosen for the psychosocial and sexual well-being

sections below, based on the same five-point scale however inversely with one being the worse or more negative situation.

Physical Wellbeing:

4. At the 1-year visit, survivors will report an average of “2” or lower for the physical well-being section (“2” indicating a physical disruption “a little of the time.”

Psychosocial Wellbeing: Any score of two or lower prompts the occupational therapist to request a physician’s order for occupational therapy to evaluate and treat to address the specific concern.

5. At the 1-year visit, survivors will report an average of “4” or higher for the psychosocial well-being section (“4” indicating a psychosocial concern “a little of the time”).

Sexual Wellbeing: Any score of two or lower prompts the occupational therapist to request a physician’s order for occupational therapy to evaluate and treat to address the specific concern.

6. At the 1-year visit, survivors will report an average of “4” or higher for the sexual well-being section (“4” indicating a psychosocial concern “a little of the time”).

The results of the BREAST-Q for survivors who participated in the program and the results of those who did not (both at one year) can then be compared to determine if the program is achieving the goal of improved quality of life for breast cancer survivors.

Supplemental Occupational Therapy Treatment Materials

During the outpatient therapy portion of the program, if the evaluating therapist determines that a deficit is present, ongoing skilled therapy will be provided. It is important that therapists be able to objectively measure change in a survivor's status during this time of therapeutic intervention. Therefore, measurements tools have been described below and provided in the Appendix for the therapists to utilize at their discretion. This information will not be used with every survivor participating in the program; it will only be used for those demonstrating a deficit and is used as a means to measure progress within the occupational therapy treatment sessions, not as an overall program evaluation method.

The provided outcome instruments were investigated to determine the best ones to use to measure individual survivor outcomes. The measures were chosen from a plethora of other measures based on their distinct ability to measure the specific areas assessed by occupational therapy and their ability to target the person-environment-occupation-and performance needs of the survivor (Christiansen et al., 2015). The occupational therapy treatment-specific assessment tools will be used to measure survivor progress in the areas of breast cancer-related lymphedema; pain; fatigue; body image; cognitive impairment; distress, depression, anxiety; bone health, musculoskeletal disorders; infertility, sexual health; psychological, spiritual, social; work, productivity; and cancer survivorship.

Breast Cancer-Related Lymphedema and Occupational Therapy

The proposed program will address lymphedema through preventative education and if a lymphedema diagnosis is made the occupational therapy practitioner can utilize the Lymphedema Life Impact Scale as a survivor specific outcome measure. The

Lymphedema Life Impact Scale (Appendix T) is a condition-specific instrument that measures the physical, functional, psychosocial, and infection concerns pertinent to survivors with extremity lymphedema. The measure will provide occupational therapy practitioners with a means to assess survivor impairments, activity and occupational limitations, and participation restrictions resulting from breast cancer-related lymphedema (Weiss, 2016). The measure blends well with the program's Person-Environment-Occupation-Performance model as it survivor specific, address the survivor's environment including home and work, directly focuses on the survivor's daily occupations and their level of performance completing these tasks.

The measure will be completed with survivors who are diagnosed with lymphedema and at the conclusion of treatment intervention. The data gathered from this scale will be used to measure the effectiveness of occupational therapy lymphedema intervention as part of the comprehensive breast cancer program. This data will provide information not only into the effectiveness of occupational therapy, but will provide possible information on areas in which the occupational therapy practitioners may require more training in which to provide better care.

Weiss & Daniel (2015) studied the validity of the Lymphedema Life Impact SCALE through a multicenter, cross-sectional study and determined that the Lymphedema Life Impact Scale is a valid and reliable tool for the assessment of severity of impairment among survivors with lymphedema. Additionally, the Lymphedema Life Impact Scale is short and quick to administer, measures treatment outcomes, and when combined with an Excel spreadsheet calculator, can figure Medicare functional impairment (Weiss & Daniel, 2015).

Lymphedema is a significant concern as a co-morbidity (Mishori, 2010) as this condition is debilitating and currently not curable (Acebedo, 2015). Therefore, the protocol addresses lymphedema prevention during Stage 1 as the occupational therapy practitioner gathers information such as involved side, upper extremity girth measurements for a baseline measure. This allows subclinical lymphedema to potentially be recognized and diagnosed earlier resulting in improved outcomes. During the post-operative Stage 2 education is provided on lymphedema prevention and in Stage 3 the survivor is assessed for lymphedema. The program provides a lymphedema specific evaluation form and daily note in the event that lymphedema is diagnosed. Furthermore, the Lymphedema Life Impact Scale (Weiss, 2016) is utilized if a lymphedema diagnosis is made in order to measure the physical, functional, and psychosocial concerns pertinent to survivors with lymphedema (Weiss, 2016). Lymphedema is again addressed in the survivor surveillance Stage 4, which continues to be addressed yearly.

Breast Cancer-Related Pain and Occupational Therapy

An additional breast cancer-related concern is pain. Pain can be a result of surgery, radiation therapy, chemotherapy and endocrine therapy (Runowicz, et al., 2016). It is estimated that 25% to 60% of breast cancer survivors experience chronic pain (Runowicz et al., 2016). Pain is a significant concern as it can significantly decrease a survivor's quality of life (Runowicz et al., 2016).

Research conducted by De Groef et al., (2015) determined that therapeutic intervention involving stretching and active exercises is effective in decreasing post-surgical concerns such as pain. They additionally reported that occupational therapy practitioners can potentially improve patient's levels and perception of pain as they treat

not only the source of the pain but the emotional effects of having chronic pain as it relates to daily tasks and engagement in activity (De Groef et al. 2015).

The literature reviewed clearly supports occupational therapy intervention to prevent and address pain. Therefore, because the proposed program focuses on increasing quality of life, pain and chronic pain must be addressed early in the program (Runowicz, et al., 2016). This was accomplished in the program through deep breathing exercises in Stage 1 (Hall, 2013) (Appendix G). Deep breathing exercises are designed to promote proper posture and movement of the thoracic cavity (Hall, 2013). Through completion of deep breathing exercise, the survivor begins to initiate proximal motion of the trunk in preparation for post-surgical exercises. Therapeutic exercise is also addressed in Stage 2 and 3. Stage 2 provides for early intervention mastectomy exercises (Hall, 2013) (Appendix J) to decrease pain and prevent conditions that cause pain post-mastectomy such as adhesive capsulitis and decreased functional use resulting in limited range of motion which can affect participation in everyday activities (Runowicz, et al., 2016). Stage 3 continues to advance upon the original exercises with the same goal, to prevent pain and a decrease in quality of life (Hall, 2013). Lastly, pain continues to be under surveillance through Stage 4 on a yearly basis.

The National Palliative Care Research Center (2013) provides the Brief Pain Inventory for assessment of the severity of pain and its effect on survivor daily functioning. This inventory aligns with the Person-Environment-Occupation-Performance model as it addresses the person including their mood and relations with others, how pain effects their work and home environments and work tasks, along with how pain interferences with their performance of these tasks.

The Brief Pain Inventory is widely used in both research and clinical setting including MD Anderson. The Brief Pain Inventory includes the assessment of the survivors' mood, activity, work, relations with others, sleep and enjoyment in life (National Palliative Care Research Center, 2013).

The Brief Pain Inventory will be given to survivors who are experiencing pain at the discretion of the occupational therapist. Essentially, the Brief Pain Inventory will enable the occupational therapy practitioner the ability to determine baseline pain ratings and pain ratings over time. The ratings will assist with determining the effectiveness of the current therapy program. Pain is monitored very closely in the medical field and this measure could provide insights into how we are treating pain and the effectiveness of our treatment. This data could also prompt an additional referral to a physician specializing in pain management.

Breast Cancer-Related Fatigue and Occupational Therapy

It has been estimated that 28-91% of cancer survivors experience fatigue (Runowicz et al., 2016) and Polo and Smith (2017) reported that approximately 50% of cancer survivors report that fatigue significantly affects their daily routine, participation in social activities, and overall occupational performance. Given the significantly high incidence of survivor-reported fatigue in the literature, occupational therapy will be addressing this area focusing on client-specific occupational related goals.

The proposed program recommends use of the Brief Fatigue Inventory provided by the National Palliative Care Research Center (2013) for assessment of the severity of fatigue and the effect of fatigue on daily functioning of the survivor. In addition to focusing on the survivor and their performance, it additionally aligns with the program

Person-Environment-Occupation-Performance Model as it addresses the work and home environments and general activity and enjoyment of life.

It is quickly completed in approximately five minutes and has strong reliability. This inventory can provide valuable information into the pre-operative (baseline), post-operative, and discharge fatigue levels of the survivors. The ratings will assist with determining the effectiveness of the current therapy program in addressing and managing fatigue.

Breast Cancer-Related Body Image Concerns and Occupational Therapy

Body image changes can be of noteworthy concern for breast cancer survivors, affecting from 31% to 67% (Runowicz et al., 2016). Many factors contribute to body image concern including amputation of a breast, scarring, lymphedema, loss of hair, sexual dysfunction, chemo-related early menopause, skin changes, and weight changes. Additionally, because the surgical procedure significantly alters the survivor's physical appearance, body image concerns will be assessed and addressed in the proposed program at each stage in the protocol.

The Disturbance Body Image Questionnaire (Cash, 2012) will be the survivor-specific tool utilized. It is a seven-scaled item questionnaire that addresses appearance-related concerns, mental preoccupation with these concerns, associated experiences of emotional distress, and resultant impairment in social, occupational, or other important areas of functioning related to an altered body image. There are also five additional open-ended items that can provide further information for the evaluator, and lastly, it can be completed in five minutes or less (Cash, 2012).

Breast Cancer-Related Cognitive Impairment and Occupational Therapy

The literature reports that 75% of active treatment survivors experience cognitive impairment; up to 35% of cancer survivors experience change in cognitive function after treatment has ended and can persist for as long as 20 years (Runowicz et al., 2016; Janelins et al., 2014). Player et al., 2014 concluded that survivors need ways to overcome changes in concentration and memory to ensure participation in occupational therapy engagement (Player et al., 2014). It is important that occupational therapy practitioners screen patients for cognitive impairment and provide treatment to promote ongoing participation in occupations along with education for caregivers (Braveman & Hunter, 2017).

To address cognitive concerns, the proposed program will utilize The Rivermead Behavioral Memory Test. This test identifies everyday memory problems, can track changes over time and can assess a wide range of survivor abilities (Wilson et al., 2017). The Rivermead Behavioral Memory Test includes 14 subtests, which assess aspects of visual, verbal, recall, recognition, immediate and delayed everyday memory, prospective memory skills and the ability to learn new information. The test takes approximately 25-30 minutes to complete.

The Rivermead Behavioral Memory Test provides the occupational therapy practitioner with the ability to target treatment to the areas tested as deficient. These areas influence occupational engagement for the survivors and are vital to return the survivor to their prior level of function. If successful progress is not made, this test could prompt an additional referral to a physician or professional who specializes in cognitive impairments.

Breast Cancer-Related Distress, Fear of Reoccurrence, Depression, Anxiety and Occupational Therapy

In 2016, a systematic review of observation studies, researchers determined that the prevalence of depression and anxiety is 22% with a range of 13% to 56% (Runowicz et al., 2016). Lyons (2015) reported that approximately one-third of the people diagnosed with cancer would experience clinically significant distress with estimates ranging from 20% to 47%. Braveman and Hunter (2017) reported finding strong evidence that cognitive-behavioral and educational interventions were found to decrease anxiety and depression in the short term. Devereaux and Carlson (1992) stated that because occupational therapy has an explicit focus on roles, behaviors, and adaptive skills, they (occupational therapy practitioners) could play a key role in the treatment of depression and anxiety associated with cancer.

In support of the literature findings, occupational therapy will address these concerns in the proposed program. These concerns will be assessed via The PROMIS Emotional Distress Scale. This scale provides specific measurements for depression and anxiety that are for adults and applicable to the general population and for those with chronic conditions making the use with survivor's quite relevant (Northwestern University, 2017). The depression scale is six questions and the anxiety scale is seven. The data collected will guide the occupational therapy practitioner in their delivering of services in order to focus on depression and anxiety needs as these conditions can significantly affect participation in daily occupations. One limitations of the PROMIS distress scale is that the questions do not directly relate back to the survival's individual situation such as their occupations and environments. However, the scale provides the

ability to determine the areas most significantly effected. For example, a survivor may indicate that they “always” felt worthless. The occupational therapy practitioner can then use this information to prompt further evaluation such as asking when and where do you feel worthless and during what activities do you feel worthless.

Breast Cancer-Related Bone/Musculoskeletal Health and Occupational Therapy

Runowicz et al., (2016) reported that up to 80% of survivors’ experience bone loss (Runowicz, et al., 2016). Bone loss risk factors are increased when combined with other known risk factors including advanced age, prior fracture history, and family history of fractures. Cancer treatments can also result in multiple musculoskeletal changes including decreased use/pain of ipsilateral upper extremity after surgery, decreased range of motion, rotator cuff injury, adhesive capsulitis, and axillary web syndrome (Runowicz et al., 2016).

In the proposed program, occupational therapy will be assessing musculoskeletal needs through each stage. If limitations or deficits are noted, the occupational therapy practitioner can utilize the Disability of Arm, Shoulder and Hand assessment to measure survivors' physical function and symptoms with regard to several musculoskeletal disorders of the upper limb.

The Disability of Arm, Shoulder and Hand covers areas and current survivor occupations, such as activities of daily living; social, work, pain, sleep, sexual activities, and engagement in meaningful participation. The type of participation requires some amount of physical, social, and psychological functioning. Davies, Brockopp & Moe (2015) completed a study to determine if the Disability of Arm, Shoulder and Hand was a valid measure to use with survivors with breast cancer-related lymphedema. The

Disability of Arm, Shoulder and Hand is designed to measure the physical, social, and psychological functioning of an individual with dysfunction in the upper limb, therefore if a valid measure, it could prove quite beneficial as an outcomes measure. Davies et al. (2015) found strong test-retest reliability and internal consistency with the Disability of Arm, Shoulder and Hand. They concluded that the Disability of Arm, Shoulder and Hand is a reliable measure of upper extremity function among survivors with breast cancer-related lymphedema (Davies et al., 2015). The Disability of Arm, Shoulder and Hand provides occupational therapy practitioners with a way to formally measure function and progress with occupational therapy intervention while keeping the focus of our Person-Environment-Occupation-Performance Model.

Breast Cancer-Related Sexual Health and Occupational Therapy

Sexually related side effects from cancer treatments include sexual desire disorder/decreased libido (23%-64% of survivors), arousal or lubrication concerns (20%-48% of survivors), orgasmic concerns (16%-36% of survivors), and dyspareunia (35%-38% of survivors) (Runowicz et al., 2016). Sexual health concerns can decrease quality of life for the survivors and their respective partners resulting in a decreased quality of life for both (Runowicz et al., 2016).

Hill et al., (2011) studied to identify patterns of female cancer survivors' interest in receiving care for sexual concerns. They used the Sexual Health Needs Assessment Questionnaire, as it is a quick tool (five questions) to use to have the patient self-report any concerns and needs, which can then prompt appropriate treatment. Therefore, the proposed program provides for the use of the Sexual Health Needs Assessment Questionnaire. This tool does not adequately address all areas in which the proposed

program is founded on. For example, it does not address environment or performance; however, provides the occupational therapy practitioner with a prompt to focus further treatment in a more specific area of sexual dysfunction. For needs that lie outside of the occupational therapy practitioner's scope of practice, then, it will prompt a referral to a physician who specializes in sexual health.

Breast Cancer-Related Psychosocial/Spiritual Comorbidity and Occupational Therapy

Many survivors face psychosocial and spiritual deficits at various stages in their survivorship. The most frequently reported areas of deficits were the reluctance to start new relationships, worrying about family members' health, avoiding social situations, feeling fearful, and feeling depressed (Hwang et al., 2015). These researchers (Hwang et al., 2015) additionally concluded that occupational therapy practitioners are well equipped with knowledge and skills for maximizing a survivors' quality of life by addressing the survivor's needs established during the occupational profile.

The proposed program will address these concerns via use of the Faith Importance Community Address Tool. Borneman, Ferrell, Puchalski (2010) studied the Faith Importance Community Address tool, which includes faith or belief, importance of spirituality, individual's spiritual community, and interventions to address spiritual needs. Borneman et al., (2010) suggest that the Faith Importance Community Address tool is a feasible tool for clinical assessment of spirituality, therefore, providing the opportunity to enhance survivors' quality of life.

The tool is a quickly completed with only eleven questions. If the occupational therapy provider is unable to address faith and spiritual needs, then this tool will prompt a referral to a spiritual leader in the hospital or community.

Breast Cancer-Related Work/Productivity/Financial Stress and Occupational Therapy

Returning to work after breast cancer treatments is important from a societal as well as individual point of view (Tiedtke et al., 2012). As recovery rates for breast cancer increase, more women are confronted with the incapacity to return to work however (Tiedtke et al., 2012). Additionally, cancer survivors can experience difficulties returning to work and accomplishing a level of productivity similar to their healthy counterparts due to the physical and emotional changes (Feuerstein, 2005).

While the survivor may not be actively working during their treatment, typically, the plan is for them to return to work and productive living. Occupational therapy practitioners can utilize the Work Productivity Activity Impairments Questionnaire to address work and productivity related needs. Reilly (2002) provides the Work Productivity Activity Impairment Questionnaire, which is designed to address impairments associated with work, productivity, and activity in general. The occupational therapy practitioners' assessment may prompt additional treatment interventions such as an on-site ergonomic assessment in order to return the survivor to active work duty.

Chapter 5: Discussion

Chapter 5 provides a discussion of best practice based on the information gathered during this capstone project. Conclusions resulting from this project will also be presented and recommendations will be made for practice and further research in this area.

Purpose of the Project

The purpose of this project was to determine the components needed in a comprehensive breast cancer care program, develop an occupational therapy evaluation and intervention protocol for this program, share the program and protocol with the Senior Vice President of Parkview Regional Medical Center's Cancer Institute, and develop program evaluation measures. Combining evidence provided from the literature and from the various areas/individuals studied has ensured that the purposed comprehensive breast cancer program includes all aspects of best practice and is supported by the literature.

Best Practice: Literature

Review of the literature demonstrated that Memorial Sloan Kettering provided the most comprehensive services; therefore, their model is utilized as a foundation for the proposed program. In addition to this foundation, the proposed program includes services provided by several other top cancer centers. These services address the potential comorbidities from breast cancer and include breast cancer-related lymphedema; body image; distress/depression/anxiety; sexual health; psychosocial/spiritual/social; and work productivity. These services were then

combined with a prospective surveillance model to create the protocol which spans throughout survivorship.

Best Practice: Experts

Experts interviewed all agreed that a comprehensive breast cancer program would require that the ordering of services be protocol-driven and survivor-centered to ensure that services are consistently provided to each survivor and monitored throughout survivorship. The experts also agreed that if a program is not individualized and survivor-centered, the program will not be successful in providing the best possible care to each survivor. Experts believed that offering protocol-driven services using a prospective surveillance model would also provide for the opportunity to catch sub-clinical co-morbidities before they become a much larger and concerning issue.

Best Practice: Residency

The experts interviewed and residency observations indicate that a comprehensive program must be protocol driven, provide a clearly understood intervention process, and that the program should provide for long-term survivor surveillance to address potential long-term needs. The residency site attended also provides services that are in alignment with some of the top-rated cancer centers in the US. Services include animal-assisted therapy, a lymphedema program, bra prosthetics and fittings, cosmetology/wig boutique, distress screening, sleep clinic, financial and genetics counseling, an amazing gift shop which is breast cancer specific, infertility clinic, nutrition services, pain management, spiritual and psychological support, smoking cessation, support groups on-site, and a survivor resource library. Lastly, the residency experts agreed that the program must be

evaluated to determine which aspects of the comprehensive program are successful and provide information for on-going program improvement.

Best Practice: International Cancer Summit

Information obtained from participation in the International Cancer Summit indicates that comprehensive breast cancer care must be evidenced-based, client-centered, and that occupational therapy practitioners need to be a part of the team. Ironically, despite the many speakers who discussed the value of occupational therapy, there were no occupational therapy presenters. Therefore, having occupational therapy presenters at this annual summit is highly recommended.

Best Practice: Continuing Education

Participation in continuing education activities concludes that best practice includes occupational therapy services and that occupational therapy practitioners are highly skilled to address cancer-related physical, cognitive, and psychosocial concerns. Additionally, occupational therapy practitioners should be addressing cancer-related fatigue and lymphedema and be an active member on all breast cancer oncology teams.

Best Practice: Survivors

Survivors provided many insights into their personal experience with having cancer and being a survivor. They reinforced the importance of client-centered and individualized care as they each have very different and unique needs. They spoke of the importance of consistent care between survivors and provided the example that if one support group member received education on lymphedema and another did not, then this left the individual who did not receive education confused, fearful, and feeling like they were not getting comprehensive care.

Implications for Occupational Therapy in Breast Cancer Rehabilitation

This capstone project provides insights from various stakeholders into the breast cancer process and provides guidance to create a comprehensive, survivor-centered, science-driven and outcomes-based program designed to address the occupational therapy specific needs of survivors. Unless educated in the healthcare arena and particularly within breast cancer, survivors typically have little to no understanding of the medical consequences of this diagnosis. Therefore, survivors require occupational therapy services in order to learn about their unique medical situation in order to make sense of the condition, be able to make medical decisions, and be able to apply recommendations related to breast cancer for life-long quality of life. Additionally, because occupational therapy practitioners often have the benefit of spending more time with the survivors, they are often the healthcare providers that are able to detect sub-clinical concerns first, such as lymphedema.

Observational learning can occur throughout the program as aspects of self-care such as lymphedema precautions and post-operative exercises are taught to survivors. Use of the Adult Learning Theory supports the process of facilitating and coaching throughout the program for adult learners (Malick et al., 2008). This provides insights into the way in which we educate survivors for optimal learning. For example, giving a survivor a 242-page handbook without further education as to the sections that apply to them may not prove successful in keeping the survivors attention and may add to their feelings of being overwhelmed. We must use a method of demonstration, practice, and return demonstration of information (demonstration can simply mean the survivor is paraphrasing back to the healthcare practitioner what she has learned and understood).

This situation enables the survivor to take control of their life after being diagnosed with cancer. Taking control enables the survivor to be a driving force in their care versus a passive component of their care, thus taking control of their situation. Fisher and Howell (2010) report that self-efficacy can be developed and enhanced through several methods such as mastering challenges, vicarious modeling, and social persuasion. These methods are threaded throughout the development of the program, as survivors master each stage of their care and the healthcare team provides optimal modeling for best learning.

Without the provision of a comprehensive breast cancer program, survivors in the region served by Parkview Regional Medical Center will not receive services that have been deemed best practice. Without receiving best-practice care, these survivors are at an increased risk of sub-standard care putting them at higher risk for costly complications over their survivorship. This higher risk could result in preventable co-morbidities and a decreased quality of life. Additionally, this can have significant impacts on the financial concerns surrounding additional health care costs both acutely and long-term over the survivors' lifespan.

Studies by Hunter et al., (2017); Fleischer and Ito (2016) Pergolotti, et al., (2015); Pergolotti, et al., (2016); and Sleight and Stein-Duker (2016) confirmed that breast cancer-related comorbidities can significantly affect a survivor's quality of life. Occupational therapy practitioners are trained to address the physical, psychosocial, and cognitive aspects of having cancer and cancer-related comorbidities. Sleight and Stein-Duker, (2016) agree stating that cancer survivors report a need for increased psychosocial and education-based supportive care services and that occupational therapy practitioners contribute a unique focus to this process. The focus on function enables a return to

activity and therefore increases a survivors' quality of life. Developing and implementing a comprehensive breast cancer program that starts from initial diagnosis through survivorship can result in improved quality of life for survivors.

As medical knowledge and technology continue to improve, breast cancer becomes a survivable disease. However, surviving also comes with potential cancer-related comorbidities, which can result in an increase in survivors' medical needs. The medical needs warrant being addressed at the time of the survivors' diagnosis through the rest of their lives as a survivor. Utilizing a long-term surveillance model provides focus on early identification of impairments and focuses on surveillance at various junctures through the care continuum and into long-term survivorship. The prospective surveillance model's goal is early identification of impairments with timely referrals to rehabilitation professionals (Silver et al., 2013).

The results and recommendations of this capstone project will be shared with Parkview Regional Medical Center. Providing this program to Parkview Regional Medical Center's key stakeholders include dissemination to the Senior Vice President of the Cancer Institute, breast surgeons, breast cancer practitioners, and the Rehabilitation Director and occupational therapists. Dissemination of this capstone project will occur via a face-to-face meeting, which will include a presentation summarizing the study and comprehensive program. Additional dissemination plans include presenting at the 2018 American Occupational Therapy Association annual conference and at the 2018 National Lymphedema Network Conference. In addition, dissemination plans include presenting at the Indiana Occupational Therapy Association Annual 2018 spring conference. Lastly, presenting to students in an attempt to educate up and coming practitioners.

As the program progresses and program evaluation information is gathered, it is likely to lead to changes in the program design to provide optimal care and in response to survivor feedback. Additionally, another focus group could prove beneficial as survivors who participated in the program attend Parkview Regional Medical Center's breast cancer support group.

In summary, this program developed as a result of the capstone project and has provided the evidence and support through literature, expert interviews, onsite residency, continuing education, and a breast cancer survivor-specific focus group to support a comprehensive breast cancer program. The proposed comprehensive occupational therapy breast cancer program has been described in detail including an occupational therapy four-stage protocol with detailed educational information that is to be provided to the survivor at each stage. Additionally, measurement tools are provided to enable the therapist to track individual survivors' occupational therapy intervention outcome measures (Appendix U) in the outpatient setting. Areas for further study include determining the impact of occupational therapy intervention on length of stay, unanticipated readmissions and emergency department visits, perioperative complications, short-term impairments, long-term impairments, late effects, cost savings, and associated disability and delays to planned post-surgical rehabilitation treatment (Carli et al., 2017).

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Appendix A

Expert Interview Questions-MD Anderson

Interview Questions for Occupational Therapy Compliance Officer

1. What is your current position at MD Anderson?
2. How would you describe a typical day in an occupation based cancer program?
3. How did you get your start in cancer rehabilitation?
4. How do you see OT's future role in cancer care?
5. Do you believe we as a profession are prepared to provide cancer care?
6. What do you feel is the most important aspect of cancer care?
7. What do you feel is most often neglected in cancer care/gaps in care?
8. Describe OT's perfect role in cancer care...pre-hab? Long-term follow-up?
9. Do you see role delineation conflicts in cancer care? OTs, RNs, PTs?
10. What do you see as MD Anderson's rehabilitation strength in providing cancer care?
11. What do you see as an area for growth MD Anderson's cancer care?
12. Are there reimbursement issues with OTs providing preventative care for individuals post diagnosis but prior to the start of cancer treatment?
13. What is an area of cancer research you feel OTs need to be doing more of?
14. What model or frame of reference do you believe is best for a breast cancer program?
15. What advice would you give a new cancer institute on designing a comprehensive program...what should be included, not overlooked, avoided, etc.

Interview Questions for Director of Rehabilitation

1. How do you envision OTs role with individuals with cancer?
2. Does your vision differ from what you are currently seeing in practice?
3. Do you believe OTs are prepared to provide quality comprehensive cancer care?
4. What areas of cancer should we (OTs) be doing more in regards to research?
5. Do you see role delineation conflicts in cancer care with OTs, PTs, RNs?
6. What is OTs greatest gift with cancer care?
7. What model or frame of reference do you believe is best for a breast cancer program?
8. What advice would you give a director on starting a comprehensive cancer care program?

Appendix B

Expert Interview Questions-PhD Psychometrician

1. Having worked in the area of breast cancer support, how do you envision that occupational therapy practitioners could provide services to individuals with breast care which ultimately would improve their quality of life? Describe the services and how you believe the patient would benefit (psychosocially, physically, spiritually, etc.).
2. What gaps in care have you seen with individuals going through breast cancer treatments and also throughout survivorship?
3. In a perfect world, how would you envision services improving for individuals with breast cancer?
4. Do you believe entry-level occupational therapists, physical therapists, nurses are prepared to work specifically with individuals with breast cancer? From all aspects of providing comprehensive care to the patient to being able to handle the emotional tolls of working with individuals with cancer.
5. What areas of research would you like to see more occupational therapy practitioners engaging in?
6. Is there a theoretical model or frame of reference you have found particularly beneficial when working with individuals with breast cancer?
7. In your opinion, how could occupational therapy practitioners work in preventive care of those at risk for breast cancer?
8. In your opinion, how could occupational therapy practitioners work in long-term survivorship/wellness roles with survivors?
9. Not all individuals with breast cancer chose to attend support groups, what is an alternative option for them to gain knowledge and also support?
10. Have you found online support groups beneficial?
11. What, in your opinion, is the best way to educate patients (hand-outs, DVDs, thumb drive, online links and online videos, face to face)?
12. What about hospital environments/contexts could be changed to improve the breast cancer patient experience?
13. What reading level do you feel all patient materials should be written to?
14. Is there anything else you would like to share?

Appendix C

International Cancer Rehabilitation Summit Course Outline



Friday, November 11, 2016		
Time	Topic	Location
3:00 pm - 4:00 pm	Registration	Grand Salon Foyer
4:00 pm - 4:05 pm	Opening Remarks Michael D. Stubblefield, MD National Medical Director for Cancer Rehabilitation Select Medical	Salon III
4:05 pm - 4:15 pm	The "Why" of Cancer Rehabilitation? David Chernow, JD President and Chief Executive Officer Select Medical	Salon III
4:15 pm - 5:00 pm	Cancer Survivorship in the United States - Envisioning the Future Julia Rowland, PhD Director, Office of Cancer Survivorship National Cancer Institute	Salon III
5:00 pm - 5:45 pm	Cancer Rehabilitation in the United States - Envisioning the Future Michael D. Stubblefield, MD National Medical Director for Cancer Rehabilitation Select Medical	Salon III
5:45 pm - 6:00 pm	Break	Salon Foyer
6:00 pm - 6:45 pm	The Tie That Binds - Integrating Services in Cancer Survivors Catherine Alfano, MS, PhD Vice President for Cancer Survivorship American Cancer Society	Salon III

Saturday, November 12, 2016		
Time	Topic	Location
7:00 am - 8:00 am	Registration	Grand Salon Foyer
7:00 am - 8:00 am	Breakfast	Salons I & II
8:00 am - 8:05 am	Opening Remarks Michael D. Stubblefield, MD National Medical Director for Cancer Rehabilitation Select Medical	Salon III
8:05 am - 9:00 am	Medical Management of Breast Cancer Patricia Ganz, MD	Salon III
9:00 am - 10:00 am	Principles of Breast Cancer Resection and Reconstruction Babak J. Mehrara, MD Memorial Sloan-Kettering Cancer Center	Salon III
10:00 am - 10:15 am	Break	Salon Foyer
10:15 am - 11:15 am	Identification, Evaluation, and Rehabilitation of Neuromuscular, Musculoskeletal, Pain and Functional Disorders in Breast Cancer Survivors Michael D. Stubblefield, MD National Medical Director for Cancer Rehabilitation Select Medical	Salon III
11:15 am - 12:00 pm	Identification, Evaluation, and Rehabilitation of Post-mastectomy Syndrome Eric M. Wisotzky, MD Director of Cancer Rehabilitation MedStar NRH	Salon III
12:00 pm - 1:00 pm	Lunch	Salons I & II
1:00 pm - 2:00 pm	Identification, Evaluation, and Rehabilitation of Fatigue in Breast Cancer Survivors Margaret McNeely, PT	Salon III
2:00 pm - 3:00 pm	Identification, Evaluation, and Rehabilitation of Cognitive Dysfunction in Breast Cancer Survivors Monique Tremaine, PhD Director of Psychology & Neuropsychology Kessler Institute for Rehabilitation	Salon III
3:00 pm - 3:15 pm	Break	Salon Foyer

3:15 pm – 4:15 pm	Exercise is Medicine for Breast Cancer Survivors Kathryn Schmitz, PhD, MPH Director of Education Development Center for Public Health Initiatives University of Pennsylvania	Salon III
4:15 pm – 5:00 pm	A Case Based Approach to the Rehabilitation of Breast Cancer Survivors Michael D. Stubblefield, MD National Medical Director for Cancer Rehabilitation Select Medical	Salon III
5:00 pm – 6:30 pm	Networking Cocktail Reception	The Diplomat Room

Appendix D

Consent Form for Participation in the Focus Group Entitled

“Comprehensive Breast Cancer Care:

An Occupational Therapy Perspective”

Funding Source: Not Applicable**IRB protocol #:****Principal Investigator(s)**

Nicole Scheiman, MHS, OTR/L

Huntington University

2303 College Avenue

Huntington, Indiana 46750

386-785-5993

Co-investigator(s)

Adrienne Lauer, Ed.D. OTR/L

Nova Southeastern University

3200 S. University Drive

Ft. Lauderdale, Florida 33328

954-262-1280

For questions/concerns about your research rights, contact:

Human Research Oversight Board (Institutional Review Board or IRB)

Nova Southeastern University

(954) 262-5369/Toll Free: 866-499-0790

IRB@nsu.nova.edu

Nova Southeastern University

Occupational Therapy Department

3200 S. University Drive

Ft. Lauderdale, FL

33328

What is this program proposal about?

Purpose is to complete a focus group as part of a comprehensive program proposal for a breast cancer care center.

Why are you asking me?

You are being asked to participate as someone who meets the criteria of being a BCS and who may be able to add value to the program proposed to offer state of the art care to BCS.

continued

What will I be doing if I agree to be in the focus group?

As a participant in the focus group, you will be asked to participate in a 90 minute one-time group. You will be asked to share experiences both good and not favorable that you may have experienced during your care for breast cancer. This group will meet on the Parkview Regional Medical Center Dupont Campus. Light refreshments will be provided.

Is there any audio or video recording?

No audio or video/picture recording will occur during the focus group.

What are the dangers to me?

The procedures or activities in this focus group are considered to present minimal risk if any to you as a participant. If you have any questions about the focus group, your rights, or have a research-related injury, please contact Nicole Scheiman at 260-359-4183. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

Are there any benefits for taking part in this focus group?

You may benefit from learning about other BCS experiences.

Will I get paid for being in the focus group? Will it cost me anything?

There is no compensation for participation in the focus group. There are no costs to you or payments made to you for participating in this focus group.

How will you keep my information private?

Any information that might possibly link you directly to the information collected during this focus group will be maintained on a password protected computer by the PI. No one besides the PI and co-investigators will have access to the data at any time.

Participation in the focus groups requires the PI as well as participant members to maintain the utmost confidentiality in relation to participation. In order to maintain privacy and confidentiality, you agree to not discuss or disclose by any means your participation or that of another focus group member.

continued

At the conclusion of the focus group, any forms with identifiable data produced as a part of the focus group will be shredded using a diamond –cut shredder and disposed of only after shredding. Identifiable digital data will be permanently deleted. The retention period of will be 3 years (36 months) from the conclusion of the focus group.

All of the information obtained in this focus group is strictly confidential unless disclosure is required by law. Only the IRB, regulatory agencies, the PI and co-investigators may review focus group records.

What if I do not want to participate or I want to leave the focus group?

You have the right to leave the focus group at any time or decline to participate. If you do decide to leave or you decide not to participate, you will not experience any penalty or loss of services you have a right to receive. If you choose to withdraw, any information collected about you **before** the date you leave the focus group will be kept in the records for 36 months from the conclusion of the focus group and may be used as a part of the focus group.

Other Considerations: If significant new information relating to the focus group becomes available, which may relate to your willingness to continue to participate, this information will be provided to you by the investigators.

Voluntary Consent by Participant:

By signing below, you indicate that

- this focus group has been explained to you
- you have read this document or it has been read to you
- your questions about this focus group have been answered
- you have been told that you may ask the researchers any focus group related questions in the future or contact them in the event of a research-related injury

- you have been told that you may ask Institutional Review Board (IRB) personnel questions about your focus group rights
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the focus group entitled “Comprehensive Breast Cancer Care: An Occupational Therapy Perspective”

Participant's Signature: _____ Date: _____

Participant's Name: _____ Date: _____

Signature of Person Obtaining Consent: _____

Date: _____



I

MEMORANDUM

To: **Nicole Scheiman**
College of Health Care Sciences

From: **Rose Colon, PhD,**
Center Representative, Institutional Review Board

Date: **November 16, 2016**

Re: **IRB #: 2016-552; Title, "Comprehensive Breast Cancer Rehabilitation: Best Practice-What is it?"**

I have reviewed the above-referenced research protocol at the center level. Based on the information provided, I have determined that this study is exempt from further IRB review under **45 CFR 46.101(b) (Exempt Category 2)**. You may proceed with your study as described to the IRB. As principal investigator, you must adhere to the following requirements:

- 1) **CONSENT:** If recruitment procedures include consent forms, they must be obtained in such a manner that they are clearly understood by the subjects and the process affords subjects the opportunity to ask questions, obtain detailed answers from those directly involved in the research, and have sufficient time to consider their participation after they have been provided this information. The subjects must be given a copy of the signed consent document, and a copy must be placed in a secure file separate from de-identified participant information. Record of informed consent must be retained for a minimum of three years from the conclusion of the study.
- 2) **ADVERSE EVENTS/UNANTICIPATED PROBLEMS:** The principal investigator is required to notify the IRB chair and me (954-262-5369 and Rose Colon, PhD, respectively) of any adverse reactions or unanticipated events that may develop as a result of this study. Reactions or events may include, but are not limited to, injury, depression as a result of participation in the study, life-threatening situation, death, or loss of confidentiality/anonymity of subject. Approval may be withdrawn if the problem is serious.
- 3) **AMENDMENTS:** Any changes in the study (e.g., procedures, number or types of subjects, consent forms, investigators, etc.) must be approved by the IRB prior to implementation. Please be advised that changes in a study may require further review depending on the nature of the change. Please contact me with any questions regarding amendments or changes to your study.

The NSU IRB is in compliance with the requirements for the protection of human subjects prescribed in Part 46 of Title 45 of the Code of Federal Regulations (45 CFR 46) revised June 18, 1991.

Cc: **Adrienne Lauer, Ed.D.**

Recruitment Flier

**INVITATION TO PARTICIPATE IN A BREAST CANCER
FOCUS GROUP/INDIVIDUAL INTERVIEW****Who:**

Women (18 years old or older) who are breast cancer survivors who are not currently receiving medical treatment for breast cancer (cancer free) but did receive care for breast cancer through Parkview Regional Medical Center.

What:

A focus group or individual interview, sharing your experiences and ideas about breast cancer care.

Where/When:

To be determined/scheduled.

Why:

Individuals who have experienced the journey of becoming a breast cancer survivor know first-hand about their care. We want to hear what aspects of care went well and your ideas and suggestions for making care even better

Questions:

Please contact Nicole Scheiman at: 260.359.4183 or email: nscheiman@huntington.edu to confirm participation.

Focus Group Questions

1. What education if any, did you receive before having surgery? What format was this education provided (verbal, written, etc.) and who provided it?
2. What education did you receive after surgery? What format was this education provided (verbal, written, etc.) and who provided it?
3. What education, if any, are you receiving about your care now/survivorship? If you are receiving education, what format are you receiving it in and who is providing it?
4. Where did/do you get information about lymphedema and any concerns you have about using your arm?
5. Think back to when you were receiving care here at Parkview, what do you believe is the best aspect of their program?
6. Which health care team or member provided the best care you received?
7. Was an occupational therapy practitioner involved in your care?
8. Think back to when you were receiving care here at Parkview, what do you believe needs improved upon the most/what can we do to make the care better with regard to rehabilitation?
9. Of all the things we discussed here today, what to you is the most important?
10. Is there anything else you would like to share about your experiences with Parkview's Cancer Program?

Appendix E

Occupational Therapy
Pre-Operative Breast Cancer Evaluation

Patient's Name _____ Age/Sex _____ DOB _____

Referring Physician _____ Onset Date _____ Eval Date _____

Medical Dx _____ Treatment Dx ICD-10 _____

Surgery Scheduled For: _____

SUBJECTIVE EXAM:

Medical History:

Surgical History:

Chief Concerns/Hx/Onset: _____

Medications:

Allergies:

Assistive Device: _____ Occupation/Activity: _____

Hand Dominance _____ Type of Residence/Stairs: _____

Support Available: _____

Patient's Goals:

Precautions/Contraindications:

Numbness/Tingling/Altered
Sensation: _____

Any pain/discomfort: Yes No

Pain: 0 1 2 3 4 5 6 7 8 9 10

__Superficial __Deep __Tingling/Numb __Shooting __Throbbing
__Dull __Sharp __Aching __Continuous __Intermittent
__Other _____

Comments: _____

Any prior infections: Yes No Location _____

Body Image Concerns:

Cognitive Concerns:

Distress/Depression/Anxiety:

Spiritual Needs:

Cultural Considerations:

OBJECTIVE EXAM:**Cognition and Learning Preferences:**

Alert and Oriented to: Person Time Place

Follow Commands: 1-step 2-step 3 or more steps

Understands and can apply basic information: Yes No

Able to actively participate and follow through: Yes No

Learning barriers: Vision Hearing Unable to read Unable to understand

Language: _____

Other _____

How does patient learn best: Pictures Reading Listening Demonstration

Other _____

Systems Review:

Cardiovascular/Pulmonary: ___ impaired ___ not impaired _____

Integumentary: ___ impaired ___ not impaired _____

Musculoskeletal: ___ impaired ___ not impaired _____

Neuromuscular: ___ impaired ___ not impaired _____

Skeletal ___ impaired ___ not impaired _____

Patient Photos Taken with Signed Consent: ___ yes ___ no photos taken

Circumferential Measurements: See attached sheet.

Grip Strength in pounds: R _____ L _____

Vitals: Heart Rate: _____ BP: ____/____ Oxygen Sats: _____ Weight: _____

Posture/Gross Symmetry: _____

ROM: AROM/AAROM

UPPER EXTREMITY	R	L
Shoulder		
Elbow		
Wrist		
Fingers		

Comments: _____

Muscle Strength

UPPER EXTREMITY	R	L
Shoulder		
Elbow		
Wrist		
Hand		

Comments: _____

Functional Activities: ADLs/IADLsKey: Independent **Modified Independent** Stand-By AssistanceContact **Guard Assistance** **Minimum Assistance** **Moderate Assistance****Maximum Assistance**

Grooming	_____	Reaching top cabinets	_____
Bathing UE	_____	Reaching low cabinets	_____
Bathing LE	_____	Carry laundry baskets	_____
Dressing UE	_____	Housekeeping	_____
Dressing LE	_____	Shopping	_____
Closures	_____	Yard Work	_____

Comments: _____

Mobility Key: Independent **Modified Independent** Stand-By AssistanceContact **Guard Assistance** **Minimum Assistance****Moderate Assistance** **Maximum Assistance**

Regular exercises _____ Leisure activities: _____

Assessment _____

Plan of Care

Patient agreeable to POC: Yes No _____

Rehab Potential: Good_____ Fair_____ Poor_____

Goals and plan discussed with patient/family: Yes_____ No_____

Time In: _____ Time Out: _____

Therapist's Signature_____ Date_____

Physician's Signature_____ Date_____

AOTA OCCUPATIONAL PROFILE TEMPLATE

"The occupational profile is a summary of a client's occupational history and experiences, patterns of daily living, interests, values, and needs" (AOTA, 2014, p. S13). The information is obtained from the client's perspective through both formal interview techniques and casual conversation and leads to an individualized, client-centered approach to intervention.

Each item below should be addressed to complete the occupational profile. Page numbers are provided to reference a description in the *Occupational Therapy Practice Framework: Domain and Process, 3rd Edition* (AOTA, 2014).

Client /Date:

Client Report	Reason the client is seeking service and concerns related to engagement in occupations	Why is the client seeking service, and what are the client's current concerns relative to engaging in occupations and in daily life activities? (This may include the client's general health status.) <input type="text"/>	
	Occupations in which the client is successful (p. S5)	In what occupations does the client feel successful, and what barriers are affecting his or her success? <input type="text"/>	
	Personal interests and values (p. S7)	What are the client's values and interests? <input type="text"/>	
	Occupational history (i.e., life experiences)	What is the client's occupational history (i.e., life experiences)? <input type="text"/>	
	Performance patterns (routines, roles, habits, & rituals) (p. S8)	What are the client's patterns of engagement in occupations, and how have they changed over time? What are the client's daily life roles? (Patterns can support or hinder occupational performance.) <input type="text"/>	
What aspects of the client's environments or contexts does he or she see as:			
Supports to Occupational Engagement		Barriers to Occupational Engagement	
Environment	Physical (p. S28) (e.g., buildings, furniture, pets)	<input type="text"/>	<input type="text"/>
	Social (p. S28) (e.g., spouse, friends, caregivers)	<input type="text"/>	<input type="text"/>
Context	Cultural (p. S28) (e.g., customs, beliefs)	<input type="text"/>	<input type="text"/>
	Personal (p. S28) (e.g., age, gender, SES, education)	<input type="text"/>	<input type="text"/>
	Temporal (p. S28) (e.g., stage of life, time, year)	<input type="text"/>	<input type="text"/>
	Virtual (p. S28) (e.g., chat, email, remote monitoring)	<input type="text"/>	<input type="text"/>
Client Goals	Client's priorities and desired targeted outcomes (p. S34)	Consider: occupational performance—improvement and enhancement, prevention, participation, role competence, health and wellness, quality of life, well-being, and/or occupational justice. <input type="text"/>	

CONSENT (RELEASE) TO PHOTOGRAPH

I, _____, a patient at _____ hereby authorize the attending Therapist or other designated person(s) to take:

Photographs of appropriate parts of my body for (specify):

- a. To provide visual demonstration of the progress being made.
- b. Document treatment outcomes in a pictorial fashion.
- c. To use the pictures for future purposes to include education and/or marketing for patients, physicians, therapists, and students.

I understand that any photographs taken will be placed in and remain part of my medical record.

I waive any and all rights I may have to any claims for payment in connection with any use of said photographs.

I release _____ from any and all liability associated with the use or reuse of said photographs or inadvertent revelation of identifying information or images.

I understand I may withdraw this consent in writing at any time; however, it will not have any effect on any actions taken prior to receiving the revocation.

I understand that my medical care is not dependent upon me signing this consent and that I may refuse to have my photographs taken.

I have read the content of this consent/release. I have been given the opportunity to ask, questions and all of my questions have been answered to my satisfaction. I fully understand the contents of this consent/release. This consent/release shall be binding upon me, my heirs and legal representatives.

Patient's Signature _____ Date _____
Legally Authorized Party _____ Date _____

Print Name of Legally Authorized Party _____

Address _____

Phone number _____

Reason for Authority _____

Relationship _____

Witness Signature _____

Date _____

Appendix F

BREAST-Q™
MASTECTOMY MODULE (PREOPERATIVE) 1.0

After reading each question, please circle the number in the box that best describes your situation. If you are unsure how to answer a question, choose the answer that comes closest to how you feel. Please answer all questions.

1. With your breast area in mind, in the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
a. How you look in the mirror <u>clothed</u> ?	1	2	3	4
b. How comfortably your bras fit?	1	2	3	4
c. Being able to wear clothing that is more fitted?	1	2	3	4
d. How you look in the mirror <u>unclothed</u> ?	1	2	3	4

2. With your breast area in mind, in the past 2 weeks, how often have you felt:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Confident in a social setting?	1	2	3	4	5
b. Emotionally able to do the things that you want to do?	1	2	3	4	5
c. Emotionally healthy?	1	2	3	4	5
d. Of equal worth to other women?	1	2	3	4	5
e. Self-confident?	1	2	3	4	5
f. Feminine in your clothes?	1	2	3	4	5
g. Accepting of your body?	1	2	3	4	5
h. Normal?	1	2	3	4	5
i. Like other women?	1	2	3	4	5
j. Attractive?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

BREAST-Q™
MASTECTOMY MODULE (PREOPERATIVE) 1.0

3. In the past 2 weeks, how often have you experienced:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Neck pain?	1	2	3	4	5
b. Upper back pain?	1	2	3	4	5
c. Shoulder pain?	1	2	3	4	5
d. Arm pain?	1	2	3	4	5
e. Rib pain?	1	2	3	4	5
f. Pain in the muscles of your chest?	1	2	3	4	5
g. Difficulty lifting or moving your arms?	1	2	3	4	5
h. Difficulty sleeping because of discomfort in your breast area?	1	2	3	4	5
i. Tightness in your breast area?	1	2	3	4	5
j. Pulling in your breast area?	1	2	3	4	5
k. Nagging feeling in your breast area?	1	2	3	4	5
l. Tenderness in your breast area?	1	2	3	4	5
m. Sharp pains in your breast area?	1	2	3	4	5
n. Shooting pains in your breast area?	1	2	3	4	5
o. Aching feeling in your breast area?	1	2	3	4	5
p. Throbbing feeling in your breast area?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

**BREAST-Q™
MASTECTOMY MODULE (PREOPERATIVE) 1.0**

4. Thinking of your sexuality, how often do you generally feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable
a. Sexually attractive in your clothes?	1	2	3	4	5	N/A
b. Comfortable/at ease during sexual activity?	1	2	3	4	5	N/A
c. Confident sexually?	1	2	3	4	5	N/A
d. Satisfied with your sex-life?	1	2	3	4	5	N/A
e. Confident sexually about how your breast area looks when <u>unclothed</u> ?	1	2	3	4	5	N/A
f. Sexually attractive when <u>unclothed</u> ?	1	2	3	4	5	N/A

Review copy
Do not use without permission

Please check that you have answered all the questions

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BREAST-Q-MastectomyModule-Preoperative_AU1.0_eng-USof.rtf

Appendix G

Occupational Therapy TOOLKIT**Prevention and Control of Upper Extremity Lymphedema**

Check all areas of your arm(s) everyday for signs of problems such as swelling, hardness, a rash, itching, redness, pain, areas that feel hot, sores or cuts. Report concerns to your doctor.

Know the Early Signs of Edema

Your arm(s) feels tight and heavy.
Your jewelry and clothing feel tight.
Measure your arm(s) and compare to your baseline measurements

Protect Your Arm from Injury and Infection

Keep your arm(s) as clean as possible. Bath with a mild soap and water and dry Gently. Take care of your fingernails and avoid cutting your cuticles.

Protect your skin.

- Use a low pH lotion to keep your skin from drying or cracking.
- Use sunscreen and insect repellent when you are outside.
- Shave with an electric razor.
- Wear gloves when gardening, doing housework or using the oven.
- Avoid extreme hot or cold such as ice packs, heating pads and hot tubs.

Don't overtire your arm(s).

- Avoid vigorous repetitive movements such as scrubbing.
- Limit lifting to no more than 5 pounds.
- Don't carry heavy over-the-shoulder bags on your affected side(s).

Elevate your arm(s) above the level of your heart whenever possible, particularly at night.

Avoid have your blood pressure taken in the affected arm(s).

Wear loose jewelry and clothes without tight bands.

Do not allow an injection, blood draw or acupuncture in the affected arm(s)

You can order a lymphedema alert bracelet from the National Lymphedema Network (<http://www.lymphnet.org> or 1-800-541-3259).

Appendix H
Deep Breathing Exercises

Occupational Therapy **TOOLKIT**
Deep Breathing Exercise

Deep breathing is combining pursed lip breathing and diaphragmatic breathing.

This exercise will help maintain the normal movement of your chest, making it easier for your lungs to expand. Continue these deep-breathing exercises indefinitely.

Perform this exercise 5-6 times a day. Take 5-6 deep breathes each session.

Instructions:

1. Sit in a comfortable position with your back supported or resting comfortably in bed in a semi-reclined position.
2. Place one hand on your stomach above the naval. Place your other hand on your chest.
3. Locate your diaphragm with a quick "sniff" or a few short pants.
4. Exhale slowly through pursed lips and gently push in with the hand that is on the stomach. The hand on your chest should be still.
5. Inhale deeply through your nose and allow the hand on your stomach to rise with the expanding diaphragm. The hand on your chest should be still.



Appendix I

Occupational Therapy
Inpatient/Post-Operative Breast Cancer Evaluation

Patient's Name _____ Age/Sex _____
DOB _____
Referring Physician _____ Onset Date _____
Eval Date _____
Medical Dx _____ Treatment Dx ICD-10 _____
Next MD Appt: _____

SUBJECTIVE EXAM:

Medical History:

Surgical History:

Chief Complaints/Hx/Onset: _____

Medications:

Allergies:

Assistive Device: _____ Occupation/Activity: _____

Hand Dominance _____ Type of Residence/Stairs: _____

Support Available: _____

Patient's Goals:

Precautions/Contraindications:

Numbness/Tingling/Altered Sensation: _____

Any pain/discomfort: Yes No

Pain: 0 1 2 3 4 5 6 7 8 9 10

___Superficial ___Deep ___Tingling/Numb ___Shooting ___Throbbing

___Dull ___Sharp ___Aching ___Continuous ___Intermittent

___Other _____

Comments:

Body Image Concerns:

Cognitive Concerns:

Distress/Depression/Anxiety:

Spiritual Needs:

OBJECTIVE EXAM:

Cognition and Learning Preferences:

Alert and Oriented to: Person Time Place

Follow Commands: 1-step 2-step 3 or more steps

Understands and can apply basic information: Yes No

Able to actively participate and follow through: Yes No

Learning barriers: Vision Hearing Unable to read

Unable to understand Language _____

Other _____

How does patient learn best: Pictures Reading Listening

Demonstration Other _____

Systems Review:

Cardiovascular/Pulmonary: ___ impaired ___ not impaired

Integumentary: ___ impaired ___ not impaired

Musculoskeletal: ___ impaired ___ not impaired

Neuromuscular: ___ impaired ___ not impaired

Skeletal ___ impaired ___ not impaired

Vitals: Heart Rate: _____ BP: ____/____ Oxygen Sats: _____ Weight: _____
Posture/Gross Symmetry: _____

ROM: AROM/AAROM

UPPER EXTREMITY	R	L
Shoulder		
Elbow		
Wrist		
Fingers		

Comments: _____

Functional Activities: ADLs/IADLs

Key: **Independent** **Modified Independent** **Stand-By Assistance**
 Contact Guard Assistance **Minimum Assistance**
 Moderate Assistance **Maximum Assistance**

Grooming _____

Bathing UE _____

Bathing LE _____

Dressing UE _____

Dressing LE _____

Closures _____

Comments: _____

Mobility Key: **Independent** **Modified Independent** **Stand-By Assistance**
 Contact Guard Assistance
 Minimum Assistance **Moderate Assistance** **Maximum Assistance**

In and out of bed _____ Walking _____

On and off toilet _____ Climbing stairs _____

Sit to stand _____

Assessment _____

Plan of Care

Goals and plan discussed with patient/family: Yes____ No____

Time In: _____ Time Out: _____

Therapist's Signature_____ Date_____

Physician's Signature_____ Date_____

[illegible]

CONSENT (RELEASE) TO PHOTOGRAPH

I, _____, a patient at _____ hereby authorize the attending Therapist or other designated person(s) to take:

Photographs of appropriate parts of my body for (specify):

- a. To provide visual demonstration of the progress being made.
- b. Document treatment outcomes in a pictorial fashion.
- c. To use the pictures for future purposes to include education and/or marketing for patients, physicians, therapists, and students.

I understand that any photographs taken will be placed in and remain part of my medical record.

I waive any and all rights I may have to any claims for payment in connection with any use of said photographs.

I release _____ from any and all liability associated with the use or reuse of said photographs or inadvertent revelation of identifying information or images.

I understand I may withdraw this consent in writing at any time; however, it will not have any effect on any actions taken prior to receiving the revocation.

I understand that my medical care is not dependent upon me signing this consent and that I may refuse to have my photographs taken.

I have read the content of this consent/release. I have been given the opportunity to ask, questions and all of my questions have been answered to my satisfaction. I fully understand the contents of this consent/release. This consent/release shall be binding upon me, my heirs and legal representatives.

Patient's Signature _____ Date _____
Legally Authorized Party _____ Date _____

Print Name of Legally Authorized Party _____

Address _____

Phone number _____

Reason for Authority _____

Relationship _____

Witness Signature _____

Date _____

Appendix J

Occupational Therapy **TOOLKIT****Mastectomy Exercises**

Patient Name: _____

Date: _____

Therapist Name: _____

Phone number: (____) _____

Exercise Guidelines:

Perform the checked exercises _____ time(s) per day, _____ days a week.

Exercise slowly and gently.

Remember to maintain proper posture with each exercise.

Don't hold your breath during any of the exercises. This could affect your blood pressure. Count out loud if needed.

If you experience chest pain, unusual shortness of breath, dizziness, nausea, blurred vision or other unusual symptoms while exercising, stop immediately and call 911.

Muscle soreness lasting a few days and slight fatigue are normal after exercising.

Exhaustion, sore joints, and painful muscle pulls are not normal. If you experience these symptoms, do not resume exercising until you talk with your therapist.

Additional Instructions:

1 of 4

Appendix K

Occupational Therapy
Outpatient Post-Operative Breast Cancer Evaluation

Patient's Name _____ Age/Sex _____ DOB _____

Referring Physician _____ Onset Date _____

Eval Date _____

Medical Dx _____ Treatment Dx ICD10 _____

Next MD Appt: _____

SUBJECTIVE EXAM:

Medical History:

Surgical History:

Chief Complaints/Hx/Onset: _____

Medications:

Allergies:

Assistive Device: _____

Occupation/Activity:

Hand Dominance _____ Type of Residence/Stairs:

Support Available:

Patient's Goals:

Precautions/Contraindications:

Numbness/Tingling/Altered

Sensation: _____

Any pain/discomfort: Yes No

Pain: 0 1 2 3 4 5 6 7 8 9 10

☐ Superficial ☐ Deep ☐ Tingling/Numb ☐ Shooting ☐ Throbbing
☐ Dull ☐ Sharp ☐ Aching ☐ Continuous ☐ Intermittent
☐ Other _____

Comments:

Overall Condition: Improving Worsening Stable

Any prior infections: Yes No

Location_____

Body Image Concerns:

Cognitive Concerns:

Distress/Depression/Anxiety:

Spiritual Needs:

OBJECTIVE EXAM:

Cognition and Learning Preferences:

Alert and Oriented to: Person Time Place

Follow Commands: 1-step 2-step 3 or more steps

Understands and can apply basic information: Yes No

Able to actively participate and follow through: Yes No

Learning barriers: Vision Hearing Unable to read

Unable to understand	Language
----------------------	----------

Other _____

How does patient learn best: Pictures Reading Listening

Demonstration	Other

Systems Review:

Cardiovascular/Pulmonary: ___ impaired ___ not impaired

Integumentary: ___impaired ___not impaired

Musculoskeletal: ___impaired ___not impaired

ROM: AROM/AAROM

UPPER EXTREMITY	R	L
Shoulder		
Elbow		
Wrist		
Fingers		

Comments: _____

Muscle Strength

UPPER EXTREMITY	R	L
Shoulder		
Elbow		
Wrist		
Hand		

Comments: _____

Functional Activities: ADLs/IADLsKey: **Independent** **Modified Independent** **Stand-By Assistance****Contact Guard Assistance** **Minimum Assistance****Moderate Assistance** **Maximum Assistance**

Grooming	_____	Reaching top cabinets	_____
Bathing UE	_____	Reaching low cabinets	_____
Bathing LE	_____	Carry laundry baskets	_____
Dressing UE	_____	Housekeeping	_____
Dressing LE	_____	Shopping	_____
Closures	_____	Yard Work	_____

Comments: _____

Mobility Key: **Independent** **Modified Independent** **Stand-By Assistance****Contact Guard Assistance****Minimum Assistance** **Moderate Assistance** **Maximum Assistance**

In and out of bed _____ Walking _____

On and off toilet	_____	Climbing stairs	_____
Sit to stand	_____	Regular exercises	_____
In and out of car	_____	Leisure activities	_____

Assessment _____

Plan of Care

Short Term Goals _____ Weeks

Long Term Goals _____ Weeks

Plan: Frequency _____ Duration _____ weeks

Patient agreeable to POC: Yes No

Possible barriers to treatment: _____

Interventions:

_____ Therapeutic exercises: stretching strengthening lymphatic

_____ Wound care education

_____ Scar management

_____ Patient/Caregiver/Family education

_____ Precautions

_____ Other: _____

Rehab Potential: Good _____ Fair _____ Poor _____

Goals and plan discussed with patient/family: Yes _____ No _____

Time In: _____ Time Out: _____

Outpatient Certification from: _____ to _____

Therapist's Signature _____ Date _____

Rehab MD OP Certification Statement: I certify that the program outlined above is provided under my supervision and is required for this patient. Care plan was developed by the therapist, discussed with the patient, and will be reviewed every 90 days.

Physician's Signature _____
Date _____

AOTA OCCUPATIONAL PROFILE TEMPLATE

"The occupational profile is a summary of a client's occupational history and experiences, patterns of daily living, interests, values, and needs" (AOTA, 2014, p. S13). The information is obtained from the client's perspective through both formal interview techniques and casual conversation and leads to an individualized, client-centered approach to intervention.

Each item below should be addressed to complete the occupational profile. Page numbers are provided to reference a description in the *Occupational Therapy Practice Framework: Domain and Process, 3rd Edition* (AOTA, 2014).

Client /Date:

Client Report	Reason the client is seeking service and concerns related to engagement in occupations	Why is the client seeking service, and what are the client's current concerns relative to engaging in occupations and in daily life activities? (This may include the client's general health status.) <input type="text"/>	
	Occupations in which the client is successful (p. S5)	In what occupations does the client feel successful, and what barriers are affecting his or her success? <input type="text"/>	
	Personal interests and values (p. S7)	What are the client's values and interests? <input type="text"/>	
	Occupational history (i.e., life experiences)	What is the client's occupational history (i.e., life experiences)? <input type="text"/>	
	Performance patterns (routines, roles, habits, & rituals) (p. S8)	What are the client's patterns of engagement in occupations, and how have they changed over time? What are the client's daily life roles? (Patterns can support or hinder occupational performance.) <input type="text"/>	
What aspects of the client's environments or contexts does he or she see as:			
Supports to Occupational Engagement		Barriers to Occupational Engagement	
Environment	Physical (p. S28) (e.g., buildings, furniture, pets)	<input type="text"/>	<input type="text"/>
	Social (p. S28) (e.g., spouse, friends, caregivers)	<input type="text"/>	<input type="text"/>
Context	Cultural (p. S28) (e.g., customs, beliefs)	<input type="text"/>	<input type="text"/>
	Personal (p. S28) (e.g., age, gender, SES, education)	<input type="text"/>	<input type="text"/>
	Temporal (p. S28) (e.g., stage of life, time, year)	<input type="text"/>	<input type="text"/>
	Virtual (p. S28) (e.g., chat, email, remote monitoring)	<input type="text"/>	<input type="text"/>
Client Goals	Client's priorities and desired targeted outcomes (p. S34)	Consider: occupational performance—improvement and enhancement, prevention, participation, role competence, health and wellness, quality of life, well-being, and/or occupational justice. <input type="text"/>	

CONSENT (RELEASE) TO PHOTOGRAPH

I, _____, a patient at _____ hereby authorize the attending Therapist or other designated person(s) to take:

Photographs of appropriate parts of my body for (specify):

- a. To provide visual demonstration of the progress being made.
- b. Document treatment outcomes in a pictorial fashion.
- c. To use the pictures for future purposes to include education and/or marketing for patients, physicians, therapists, and students.

I understand that any photographs taken will be placed in and remain part of my medical record.

I waive any and all rights I may have to any claims for payment in connection with any use of said photographs.

I release _____ from any and all liability associated with the use or reuse of said photographs or inadvertent revelation of identifying information or images.

I understand I may withdraw this consent in writing at any time; however, it will not have any effect on any actions taken prior to receiving the revocation.

I understand that my medical care is not dependent upon me signing this consent and that I may refuse to have my photographs taken.

I have read the content of this consent/release. I have been given the opportunity to ask, questions and all of my questions have been answered to my satisfaction. I fully understand the contents of this consent/release. This consent/release shall be binding upon me, my heirs and legal representatives.

Patient's Signature _____ Date _____

Legally Authorized Party _____ Date _____

Print Name of Legally Authorized Party _____

Address _____

Phone number _____

Reason for Authority _____
Relationship _____

Witness Signature _____

Date _____

DAILY TREATMENT RECORD**Diagnosis:** _____**Re-eval date:** _____**Date:** _____**Precautions:** ☐ Falls ☐ Lymphedema☐ **Other:** _____**Subjective:**

Patient reported a change in: ☐ medication ☐ allergy ☐ condition:

PAIN: _____/10 ☐ decreased ☐ increased ☐ no change

Affected by: _____

Treatment Interventions: ☐STM x _____ min to: ☐ decrease pain ☐ decrease soft tissue restriction ☐ i☐ Therapeutic Exercise x _____ min:

To improve: ☐ strength ☐ ROM ☐ motor control ☐ endurance ☐ flexibility☐ see flow sheet☐ NLN Risk Reduction ☐ NLN Exercise ☐ instruct on don/doffing of garments☐ instruct on garment care, wearing schedule or adjustment

Other: _____

☐ Neuromuscular Re-education x _____ min to: ☐ facilitate normalized resting posture on ☐ involved side ☐ non-involved side

☐ to decrease substitution and normalize muscle recruitment patterns for decreased pain and functional ROM

☐ balance ☐ coordination ☐ proprioception for sitting / standing activities

OBJECTIVE FINDINGS:

☐ Routine Measurements (see measurement flow sheet)

☐ Photos (with signed consent on file) – see attached

Assessment:

The patient's progress toward established goals is: excellent good fair poor

Patient requires skilled therapy services for ☐ CDT – intensive phase ☐ Modified CDT ☐ early intervention lymphedema management ☐ Cording treatment ☐ pain control ☐ ROM ☐ Strengthening ☐ Functional improvement

P: ☐ D/C Therapy ☐ Next Visit:

Therapist:

Appendix L

Occupational Therapy
Outpatient Lymphedema Evaluation

Patient's Name _____ Age/Sex _____ DOB _____
Referring Physician _____ Onset Date _____
Eval Date _____
Medical Dx _____ Treatment Dx ICD-10 _____
Next MD Appt: _____

SUBJECTIVE EXAM:

Medical History:

Surgical History:

Chief

Complaints/Hx/Onset: _____

Medications:

Allergies: _____

Assistive Device: _____

Occupation/Activity:

Previous Treatment for Lymphedema

Family History of Lymphedema:

Hand Dominance _____ Type of Residence/Stairs:

Support Available:

Patient's Goals:

Precautions/Contraindications:

Numbness/Tingling/Altered

Sensation: _____

Any pain/discomfort: Yes No

Pain: 0 1 2 3 4 5 6 7 8 9 10

__Superficial __Deep __Tingling/Numb __Shooting __Throbbing

__Dull __Sharp __Aching __Continuous __Intermittent

__Other _____

Comments: _____

Overall Condition: Improving Worsening Stable

Any prior infections: Yes No

Location _____

Symptoms of Lymphedema relieved by, if yes please circle:

Elevation Exercise Massage Garment Diuretics Compression Pump

Unable to relieve symptoms

Body Image Concerns: _____

Cognitive Concerns: _____

Distress/Depression/Anxiety: _____

Spiritual Needs: _____

OBJECTIVE EXAM:**Cognition and Learning Preferences:**

Alert and Oriented to: Person Time Place

Follow Commands: 1-step 2-step 3 or more steps

Understands and can apply basic information: Yes No

Able to actively participate and follow through: Yes No

Learning barriers: Vision Hearing Unable to read

Unable to understand Language

Other _____

How Hoes patient learn best: Pictures Reading Listening

Demonstration

Other _____

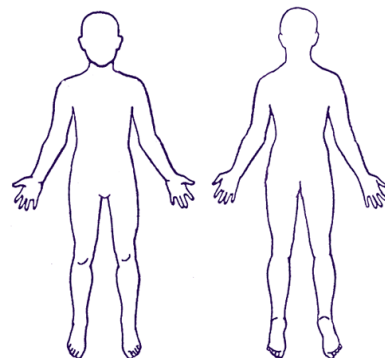
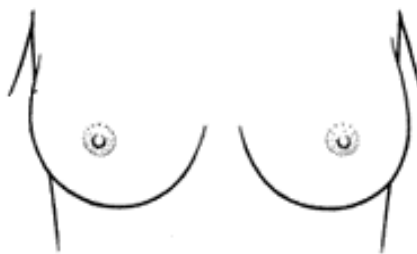
Systems Review:

Cardiovascular/Pulmonary: ___ impaired ___ not impaired
 Integumentary: ___ impaired ___ not impaired
 Musculoskeletal: ___ impaired ___ not impaired
 Neuromuscular: ___ impaired ___ not impaired
 Skeletal ___ impaired ___ not impaired

Skin Condition

SKIN CONDITION	YES	NO	Comment/Location
Ulcerations/wounds			
Contracture			
Dryness			
Other Lesions			
Lipodermatosclerosis			
Edema (Pitting/Non-Pitting)			
Pitting (degree)			
Hair Growth			
Stemmer Sign			
Scars			
Other:			

Patient Photos Taken with Signed Consent: ___ yes ___ no photos taken

Scar Locations:

Circumferential Measurements: See attached sheet.

Grip Strength in pounds: R _____ L _____

Vitals: Heart Rate: _____ BP: ____/____ Oxygen Sats: _____
Weight: _____

Posture/Gross Symmetry: _____

Balance: _____

Gait: _____

ROM: AROM/AAROM

UPPER EXTREMITY	R	L
Shoulder		
Elbow		
Wrist		
Fingers		

Comments: _____

Muscle Strength

UPPER EXTREMITY	R	L
Shoulder		
Elbow		
Wrist		
Hand		

Comments: _____

Functional Activities: ADLs/IADLs

Key: **Independent** **Modified Independent** **Stand-By Assistance**

Contact Guard Assistance **Minimum Assistance** **Moderate Assistance**

Maximum Assistance

Grooming	_____	Reaching top cabinets	_____
Bathing UE	_____	Reaching low cabinets	_____
Bathing LE	_____	Carry laundry baskets	_____
Dressing UE	_____	Housekeeping	_____
Dressing LE	_____	Shopping	_____
Closures	_____	Yard Work	_____

Comments: _____

Mobility Key: **Independent** **Modified Independent****Stand-By Assistance** **Contact Guard Assistance** **Minimum Assistance****Moderate Assistance** **Maximum Assistance**

In and out of bed	_____	Walking	_____
On and off toilet	_____	Climbing stairs	_____
Sit to stand	_____	Regular exercises	_____
In and out of car	_____	Leisure activities	_____

Assessment _____**Plan of Care****Short Term Goals** _____ Weeks

N/A	Yes	
1 _____	_____	Reduce measurements difference from _____ % to _____ %.
2 _____	_____	Improve quality tissue with reduction of fibrosis to improve health of tissue
3 _____	_____	Improve AROM of _____ UE/LE as follows
4 _____	_____	Improve strength of _____ UE/LE as follows
5 _____	_____	Independent with skin care to reduce risks of infection
6 _____	_____	Reduce pain to _____/10 in _____ UE/LE
7 _____	_____	Demonstrates _____% understanding of lymphedema/treatment /HEP

8 _____ Demonstrates _____% adherence to lymphedema precautions
 9 _____ Other functional goals

Long Term Goals _____ Weeks

N/A	Yes	
1 _____	_____	Reduce measurement difference from _____% to _____ %
2 _____	_____	Resolution of pitting edema for improved health of tissue/reduce risk of infections
3 _____	_____	Independent with self-bandaging
4 _____	_____	Patient to be at _____% of functional use of _____ UE/LE
5 _____	_____	Patient will manage lymphedema with _____% independence
6 _____	_____	Patient will follow HEP with _____% independence
7 _____	_____	Patient to be able to don/doff compression garments with _____% independence
8 _____	_____	Other functional goals _____

Before Initiating Treatment patient will need to do the following:

__ arrange for assistance with home program	__ obtain reliable transportation
__ arrange work schedule/FMLS	__ obtain further medical clearance
__ obtain bandage supplies	

Plan: Frequency _____ Duration _____ weeks Patient agreeable to
 POC: Yes No
 Possible barriers to treatment:

Interventions:

- _____ Manual Lymphatic drainage (MLD)
- _____ Compression bandaging
- _____ Self-care training: bandaging skin care self-massage
- _____ Therapeutic exercises: stretching strengthening lymphatic
- _____ Wound care education
- _____ Compression garment
- _____ Don/doff of garment
- _____ Scar management
- _____ Patient/Caregiver/Family education
- _____ Precautions
- _____ Other: _____

Rehab Potential: Good____ Fair____ Poor____

Goals and plan discussed with patient/family: Yes____ No____

Time In: _____ Time Out: _____

Outpatient Certification from: _____ to _____

Therapist's Signature _____ Date _____

Rehab MD OP Certification Statement: I certify that the program outlined above is provided under my supervision and is required for this patient. Care plan was developed by the therapist, discussed with the patient, and will be reviewed every 90 days.

Physician's Signature _____ **Date** _____

AOTA OCCUPATIONAL PROFILE TEMPLATE

"The occupational profile is a summary of a client's occupational history and experiences, patterns of daily living, interests, values, and needs" (AOTA, 2014, p. S13). The information is obtained from the client's perspective through both formal interview techniques and casual conversation and leads to an individualized, client-centered approach to intervention.

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	Occupations in which the client is successful (p. S5)	In what occupations does the client feel successful, and what barriers are affecting his or her success? <input type="text"/>	
	Personal interests and values (p. S7)	What are the client's values and interests? <input type="text"/>	
	Occupational history (i.e., life experiences)	What is the client's occupational history (i.e., life experiences)? <input type="text"/>	
	Performance patterns (routines, roles, habits, & rituals) (p. S8)	What are the client's patterns of engagement in occupations, and how have they changed over time? What are the client's daily life roles? (Patterns can support or hinder occupational performance.) <input type="text"/>	
What aspects of the client's environments or contexts does he or she see as:			
Supports to Occupational Engagement		Barriers to Occupational Engagement	
Environment	Physical (p. S28) (e.g., buildings, furniture, pets)	<input type="text"/>	<input type="text"/>
	Social (p. S28) (e.g., spouse, friends, caregivers)	<input type="text"/>	<input type="text"/>
Context	Cultural (p. S28) (e.g., customs, beliefs)	<input type="text"/>	<input type="text"/>
	Personal (p. S28) (e.g., age, gender, SES, education)	<input type="text"/>	<input type="text"/>
	Temporal (p. S28) (e.g., stage of life, time, year)	<input type="text"/>	<input type="text"/>
	Virtual (p. S28) (e.g., chat, email, remote monitoring)	<input type="text"/>	<input type="text"/>
Client Goals	Client's priorities and desired targeted outcomes (p. S34)	Consider: occupational performance—improvement and enhancement, prevention, participation, role competence, health and wellness, quality of life, well-being, and/or occupational justice. <input type="text"/>	

CONSENT (RELEASE) TO PHOTOGRAPH

I, _____, a patient at _____ hereby authorize the attending Therapist or other designated person(s) to take:

Photographs of appropriate parts of my body for (specify):

- a. To provide visual demonstration of the progress being made.
- b. Document treatment outcomes in a pictorial fashion.
- c. To use the pictures for future purposes to include education and/or marketing for patients, physicians, therapists, and students.

I understand that any photographs taken will be placed in and remain part of my medical record.

I waive any and all rights I may have to any claims for payment in connection with any use of said photographs.

I release _____ from any and all liability associated with the use or reuse of said photographs or inadvertent revelation of identifying information or images.

I understand I may withdraw this consent in writing at any time; however, it will not have any effect on any actions taken prior to receiving the revocation.

I understand that my medical care is not dependent upon me signing this consent and that I may refuse to have my photographs taken.

I have read the content of this consent/release. I have been given the opportunity to ask, questions and all of my questions have been answered to my satisfaction. I fully understand the contents of this consent/release. This consent/release shall be binding upon me, my heirs and legal representatives.

Patient's Signature _____ Date _____

Legally Authorized Party _____ Date _____

Print Name of Legally Authorized Party _____

Address _____

Phone number _____

Reason for Authority _____

Relationship _____

Witness Signature _____

Date _____

DAILY TREATMENT RECORD**Diagnosis:** _____ **Re-eval date:** _____**Date:** _____**Precautions:** ☐ Falls ☐ Lymphedema ☐**Other:** _____**Subjective:**

Patient reported a change in: ☐ medication ☐ allergy ☐ condition:

PAIN: _____/10 ☐ decreased ☐ increased ☐ no change

Affected by: _____

Treatment Interventions: ☐☐ Manual Therapy: MLD x _____ min to decongest affected region and promote improved lymphatic drainage to non-affected regionsSTM x _____ min to: ☐ decrease pain ☐ decrease soft tissue restriction ☐ improve ROM ☐ improve tissue extensibilityCompression Bandaging x _____ min to ☐ prevent re-accumulation of edema ☐ decrease limb size ☐ decrease fibrosis☐ Therapeutic Exercise x _____ min:

To improve: ☐ strength ☐ ROM ☐ motor control ☐ endurance ☐ flexibility☐ see flow sheet

☐ Self Care Mgt x _____ min to learn: ☐ bandage management ☐ meticulous skin & nail care ☐ self-bandaging ☐ self-MLD ☐ family training

☐ NLN Risk Reduction ☐ NLN Exercise ☐ instruct on don/doffing of garments ☐ instruct on garment care, wearing schedule or adjustment

☐ Other: _____

☐ Orthotic Fit/Training x _____ min to measure for garments:

☐ Neuromuscular Re-education x _____ min to: ☐ facilitate normalized resting posture on ☐ involved side ☐ non-involved side

☐ to decrease substitution and normalize muscle recruitment patterns for decreased pain and functional ROM

☐ balance ☐ coordination ☐ proprioception for sitting / standing activities

☐ **OBJECTIVE FINDINGS:**

☐ Routine Measurements (see measurement flow sheet) ☐ Photos (with signed consent on file) – see attached

Assessment:

The patient's progress toward established goals is: excellent good fair poor

Patient requires skilled therapy services for ☐ CDT – intensive phase ☐ Modified CDT ☐ early intervention lymphedema management

☐ Cording treatment ☐ pain control ☐ ROM ☐ Strengthening ☐
Functional improvement

P: ☐ D/C Therapy ☐ Next Visit:

Therapist:

Appendix M

MASTECTOMY MODULE (POSTOPERATIVE) 2.0

After reading each question, please circle the number in the box that best describes your situation. If you are unsure how to answer a question, choose the answer that comes closest to how you feel. Please answer all questions.

1. With your breast area in mind, in the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
a. How you look in the mirror <u>clothed</u> ?	1	2	3	4
b. How comfortably your bras fit?	1	2	3	4
c. Being able to wear clothing that is more fitted?	1	2	3	4
d. How you look in the mirror <u>unclothed</u> ?	1	2	3	4

2. With your breast area in mind, in the past 2 weeks, how often have you felt:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Confident in a social setting?	1	2	3	4	5
b. Emotionally able to do the things that you want to do?	1	2	3	4	5
c. Emotionally healthy?	1	2	3	4	5
d. Of equal worth to other women?	1	2	3	4	5
e. Self-confident?	1	2	3	4	5
f. Feminine in your clothes?	1	2	3	4	5
g. Accepting of your body?	1	2	3	4	5
h. Normal?	1	2	3	4	5
i. Like other women?	1	2	3	4	5
j. Attractive?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

BREAST-Q™
MASTECTOMY MODULE (POSTOPERATIVE) 2.0

3. In the past 2 weeks, how often have you experienced:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Neck pain?	1	2	3	4	5
b. Upper back pain?	1	2	3	4	5
c. Shoulder pain?	1	2	3	4	5
d. Arm pain?	1	2	3	4	5
e. Rib pain?	1	2	3	4	5
f. Pain in the muscles of your chest?	1	2	3	4	5
g. Difficulty lifting or moving your arms?	1	2	3	4	5
h. Difficulty sleeping because of discomfort in your breast area?	1	2	3	4	5
i. Tightness in your breast area?	1	2	3	4	5
j. Pulling in your breast area?	1	2	3	4	5
k. Nagging feeling in your breast area?	1	2	3	4	5
l. Tenderness in your breast area?	1	2	3	4	5
m. Sharp pains in your breast area?	1	2	3	4	5
n. Shooting pains in your breast area?	1	2	3	4	5
o. Aching feeling in your breast area?	1	2	3	4	5
p. Throbbing feeling in your breast area?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

BREAST-Q™
MASTECTOMY MODULE (POSTOPERATIVE) 2.0

4. Thinking of your sexuality, how often do you generally feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable
a. Sexually attractive in your clothes?	1	2	3	4	5	N/A
b. Comfortable/at ease during sexual activity?	1	2	3	4	5	N/A
c. Confident sexually?	1	2	3	4	5	N/A
d. Satisfied with your sex-life?	1	2	3	4	5	N/A
e. Confident sexually about how your breast area looks when <u>unclothed</u> ?	1	2	3	4	5	N/A
f. Sexually attractive when <u>unclothed</u> ?	1	2	3	4	5	N/A

5. These questions ask about your breast cancer surgeon. Did you feel that he/she:

	Definitely Disagree	Somewhat Disagree	Somewhat Agree	Definitely Agree
a. Was professional?	1	2	3	4
b. Gave you confidence?	1	2	3	4
c. Involved you in the decision-making process?	1	2	3	4
d. Was reassuring?	1	2	3	4
e. Answered all your questions?	1	2	3	4
f. Made you feel comfortable?	1	2	3	4
g. Was thorough?	1	2	3	4
h. Was easy to talk to?	1	2	3	4
i. Understood what you wanted?	1	2	3	4
j. Was sensitive?	1	2	3	4
k. Made time for your concerns?	1	2	3	4
l. Was available when you had concerns?	1	2	3	4

BREAST-Q™
MASTECTOMY MODULE (POSTOPERATIVE) 2.0

Please check that you have answered all the questions before going on to the next page

6. These questions ask about members of the medical team other than the surgeon (e.g. nurses and other doctors who looked after you in the hospital when you had your mastectomy).
 Did you feel that they:

	Definitely Disagree	Somewhat Disagree	Somewhat Agree	Definitely Agree
a. Were professional?	1	2	3	4
b. Treated you with respect?	1	2	3	4
c. Were knowledgeable?	1	2	3	4
d. Were friendly and kind?	1	2	3	4
e. Made you feel comfortable?	1	2	3	4
f. Were thorough?	1	2	3	4
g. Made time for your concerns?	1	2	3	4

7. These questions ask about members of the office staff (e.g. secretaries, office or clinic nurses).
 Did you feel that they:

	Definitely Disagree	Somewhat Disagree	Somewhat Agree	Definitely Agree
a. Were professional?	1	2	3	4
b. Treated you with respect?	1	2	3	4
c. Were knowledgeable?	1	2	3	4
d. Were friendly and kind?	1	2	3	4
e. Made you feel comfortable?	1	2	3	4
f. Were thorough?	1	2	3	4
g. Made time for your concerns?	1	2	3	4

Please check that you have answered all the questions

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BREAST-Q – Mastectomy Module-postoperative – United States/English – Original version
 BREAST-Q- Mastectomy-Post_AU2.0_eng-USot.doc

Appendix N

Occupational Therapy TOOLKIT

Stress Management and Relaxation Techniques

What Causes Stress?

- Major events
Injury, illness, moving, death of someone close to you.
- Everyday life events
Disagreements, waiting for others, not sleeping well, meeting new people, being late, feeling bored, having too much to do.

Identify the Causes of Your Stress

- Keep a log of stressful events that occur in your life for 2 weeks.

Recognize How Stress Affects You

- Physical signs
Fatigue, nightmares, tightness of the neck and shoulder muscles, headaches, high blood pressure, digestive problems, chest pain, irregular heartbeat.
- Mental signs
Memory problems, difficulty making decisions, inability to concentrate, negative thinking, racing thoughts, poor judgment, loss of objectivity.
- Emotional signs
Restlessness, anxiety, depression, anger and resentment, easily irritated, overwhelmed, lack of confidence, apathy.
- Behavioral signs
Eating more or less, sleeping too much or too little, nervous habits (e.g. nail biting, pacing), teeth grinding or jaw clenching, losing your temper, overreacting to unexpected problems.

How to Cope with Stress

- Prevent or avoid the situation.
- Change as much of the situation as possible.
- Change your response to the situation.
 - Learn to accept what cannot be changed.
 - Talk about worries and frustrations.
 - Take one thing at a time; learn to prioritize and manage time.

1 of 2

Occupational Therapy TOOLKIT

Stress Management and Relaxation Techniques

Taking Care of Yourself So You Can Handle Stress Better

- Talk to someone about your feelings.
- Eat a well-balanced diet.
- Exercise that includes stretching, strengthening and cardiovascular.
- Get enough sleep.
- Balance self-care and work with recreation.
- Do something nice for yourself every day.

Practice Relaxation and Stress Reduction Activities

- Controlled breathing
- Progressive muscle relaxation
- Guided imagery
- Self-hypnosis
- Meditation
- Prayer
- Tai Chi
- Yoga
- Listening to music.
- Looking at a pleasant scene or piece of art.

Appendix O

Occupational Therapy TOOLKIT

Mastectomy Exercises

- ☐ **Head Tilt**
Tilt your head toward your shoulder.
Repeat on the other side.

Complete _____ set(s) of _____



- ☐ **Shoulder Shrug**
Shrug your shoulders and release.

Complete _____ set(s) of _____



- ☐ **Back Stretch**
Grasp your hands together behind your back. Pull your shoulder blades together and release.

Complete _____ set(s) of _____



- ☐ **Elbow Spread**
Clasp your hands behind your neck. Bring your elbows together and then spread your elbows apart.

Complete _____ set(s) of _____



Occupational Therapy TOOLKIT

Mastectomy Exercises

☐ **Corner Stretch**

Stand facing a corner. Bend your elbows and put your forearms on the wall. Your elbows should be as close to shoulder height as possible. Move your chest toward the corner.

Complete _____ set(s) of _____

☐ **Wall Walk - Forward**

Stand with your involved arm facing the wall. Walk your fingers up the wall, and then walk them down the wall.

Complete _____ set(s) of _____

☐ **Wall Walk - Side**

Stand with your involved arm next to the wall. Walk your fingers up the wall, and then walk them down the wall.

Complete _____ set(s) of _____

☐ **Shoulder Flexion**

Hold a cane or dowel with your hands at shoulder width apart. Lift the dowel up in front as high as you can.

Complete _____ set(s) of _____



3 of 4

Occupational Therapy TOOLKIT

Mastectomy Exercises

☐ **Shoulder Abduction**

Hold a cane or dowel with your hands at shoulder width apart. Lift the dowel up to the side as high as you can. Repeat to opposite side.

Complete _____ set(s) of _____

☐ **Shoulder Side to Side**

Hold a cane or dowel with your hands at shoulder width apart. Move the dowel from side to side.

Complete _____ set(s) of _____

☐ **Shoulder Extension**

Hold the cane or dowel behind you. Keeping your elbows straight, lift the dowel away from your body.

Complete _____ set(s) of _____

☐ **Shoulder Internal Rotation**

Hold the cane or dowel behind you. Bend your elbows and lift the dowel up your back.

Complete _____ set(s) of _____

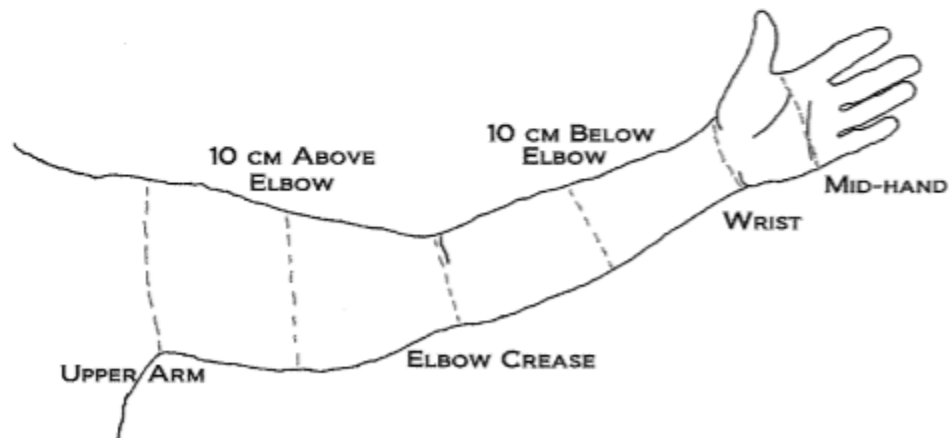


Appendix P

Occupational Therapy TOOLKIT

Measuring Your Arm Following Mastectomy

Date							
Upper arm just below the axilla							
10 cm above elbow crease							
Elbow crease							
10 cm below elbow crease							
Wrist							
Mid-hand							



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Appendix Q

Occupational Therapy TOOLKIT

Energy Conservation

Pace Yourself

1. Allow yourself enough time to complete a task without having to rush.
2. Spread heavy and light tasks throughout the day and week.
3. Don't schedule too many activities in one day.

Plan Ahead and Be Organized

1. Gather all items you will need before you start a task.
2. Keep items organized and within easy reach.

Simplify Your Tasks and Set Realistic Goals

1. Prioritize what activities are most important to you.
2. Don't think you have to do things the same way you've always done them.
3. Ask for help. Divide tasks among family and friends.
4. Use adaptive equipment when needed.
5. Use appliances to do the work for you.

Avoid Fatigue

1. Don't wait until you are tired before you stop and rest.
2. Plan rest periods throughout the day, 5-10 minutes out of every hour.
3. Sit when possible.
4. Use pursed lip breathing.
5. Do not plan activities right after a meal. Rest 20 to 30 minutes after each meal.
6. Get a good night's sleep and elevate your head when sleeping.

Avoid Unnecessary Motion

1. Limit the need to bend, reach and twist.
2. Minimize arm movements especially above your shoulder level.
3. Keep your elbows low and close to your body.
4. Support elbows on a surface when working in one place.

Use Good Posture

1. Sit and stand straight.
2. Proper body alignment balances muscles and decreases stress.
3. A stooped posture makes breathing more difficult.

Use Good Body Mechanics

1. Stand close to the object to be moved.
2. Push or pull rather than lift. Slide objects along the counter.
3. Avoid bending, reaching and twisting.
4. Carry items close to the body, keeping your back straight.
5. If you must lift, use your legs muscles rather than your back.

Appendix R

Occupational Therapy TOOLKIT

Good Posture

Be aware of your posture during daily activities. Good posture should be a part of all activities to minimize stress to your spine.

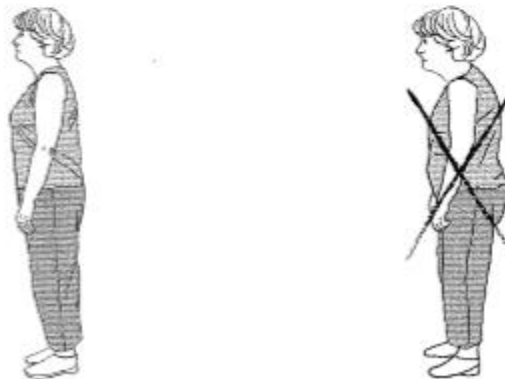
Sleeping

- Sleep on a firm mattress. A king or queen size bed allows freedom to change positions.
- Only sleep with one pillow under your head. If you need to elevate your head at night, use a foam wedge.
- When getting out of bed, log roll to one side and sit up, using your arms to help.
- The best position for sleeping is on your side with your knees slightly bent and a pillow placed in between.
- When lying on your back, place one or two pillows under your knees.



Standing

- Stand with knees slightly bent, stomach and buttock muscles tightened.
- When standing, keep activities at a comfortable height.
- Change position frequently.



Appendix S

Stage 4 Annual Automated Survivorship Surveillance Email Questions

1. Are you currently participating in a healthy lifestyle change as a result of receiving breast cancer-related care at Parkview Regional Medical Center (for example- following lymphedema precautions, exercising, periodically measuring your arm to check for swelling)?
2. Do you feel confident that the breast cancer-related healthcare provided to you at Parkview Regional Medical Center left you confident and prepared for long-term cancer survivorship?
3. After receiving breast cancer-related care at Parkview Regional Medical Center, were you able to return to doing all activities you did before having breast cancer?
4. After receiving breast cancer-related care at Parkview Regional Medical Center, do you feel your mental, emotional, and social needs were met?
5. Do you have swelling in your arm?

Second year and continuing annually

1. Do you continue to participate in a healthy lifestyle change as a result of receiving breast cancer-related care at Parkview Regional Medical Center (for example- following lymphedema precautions, exercising, periodically measuring your arm to check for swelling)?
2. Do you continue to feel confident that the breast cancer-related healthcare provided to you at Parkview Regional Medical Center left you confident and prepared for long-term cancer survivorship?
3. Are you able to participate in all the daily activities you wish to?
4. After receiving breast cancer-related care at Parkview Regional Medical Center, do you feel your mental, emotional, and social needs continue to be positive?
5. Do you have swelling in your arm?

Appendix T

Lymphedema Life Impact Scale

**LLIS****Lymphedema Life Impact Scale****version 2**

Patient Name _____ Eval _____ 10th visit _____ 20th visit _____ 30th visit _____ D/C _____

Listed below are symptoms or problems reported by many individuals with lymphedema. Please indicate to what extent these problems associated with your lymphedema has affected you in **the past week**. Circle the number which best describes your symptom level.

I. Physical Concerns (NOTE: If swelling and symptoms are the same in both limbs, rate them the same; otherwise, rate only the worst limb)

1. The amount of pain associated with my lymphedema is:	0 no pain	1	2	3	4 severe pain
2. The amount of limb heaviness associated with my lymphedema is:	0 no heaviness	1	2	3	4 extremely heavy
3. The amount of skin tightness associated with my lymphedema is:	0 no tightness	1	2	3	4 extremely tight
4. The size of my swollen limb(s) seems:	0 normal size	1	2	3	4 extremely large
5. Lymphedema affects the movement of my swollen limb(s):	0 normal movement	1	2	3	4 extremely limited
6. The strength in my swollen limb(s) is:	0 normal strength	1	2	3	4 extremely weak

II. Psychosocial Concerns

7. Lymphedema affects my body image (how I think I look):	0 not at all	1	2	3	4 completely
8. Lymphedema affects my socializing with others.	0 no interference	1	2	3	4 interferes completely

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II. Psychosocial Concerns (cont.)

9. Lymphedema affects my intimate relations with spouse or partner (rate 0 if not applicable).	0 no interference	1	2	3	4 interferes completely
10. Lymphedema "gets me down" (i.e., I have feelings of depression, frustration, or anger due to the lymphedema).	0 never	1	2	3	4 constantly
11. I must rely on others for help due to my lymphedema.	0 not at all	1	2	3	4 completely
12. I know what to do to manage my lymphedema.	0 good understanding	1	2	3	4 no understanding

III. Functional Concerns


13. Lymphedema affects my ability to perform self-care activities (i.e., eating, dressing, hygiene).	0 no interference	1	2	3	4 interferes completely
14. Lymphedema affects my ability to perform routine home or work-related activities.	0 no interference	1	2	3	4 interferes completely
15. Lymphedema affects my performance of preferred leisure activities.	0 no interference	1	2	3	4 interferes completely
16. Lymphedema affects the proper fit of clothing/shoes.	0 fits normally	1	2	3	4 unable to wear
17. Lymphedema affects my sleep.	0 no interference	1	2	3	4 interferes completely

IV. Infection Occurrence

18. In the past year, I have become ill with an infection in my swollen limb requiring oral antibiotics or hospitalization.	0	1x	2x	3x	4+
---	---	----	----	----	----

Appendix U

Individual Survivor Outcome Measurement Tools

 1903	Date: <input type="text"/> / <input type="text"/> / <input type="text"/> (month) (day) (year)	Study Name: _____ Protocol #: _____ PI: _____ Revision: 07/01/05
Subject's Initials : _____ Study Subject #: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>		

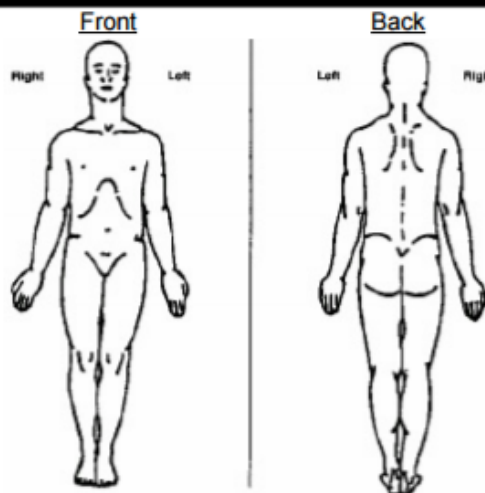
PLEASE USE
BLACK INK PEN

Brief Pain Inventory (Short Form)

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

☐ Yes ☐ No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by marking the box beside the number that best describes your pain at its **worst** in the last 24 hours.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
 No Pain Pain As Bad As You Can Imagine

4. Please rate your pain by marking the box beside the number that best describes your pain at its **least** in the last 24 hours.



☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
 No Pain Pain As Bad As You Can Imagine

5. Please rate your pain by marking the box beside the number that best describes your pain on the **average**.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
 No Pain Pain As Bad As You Can Imagine

6. Please rate your pain by marking the box beside the number that tells how much pain you have **right now**.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
 No Pain Pain As Bad As You Can Imagine

  1903	Date: <input type="text"/> / <input type="text"/> / <input type="text"/> (month) (day) (year)	Study Name: _____ Protocol #: _____ PI: _____ Revision: 07/01/05
Subject's Initials : _____ Study Subject #: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>		

PLEASE USE
BLACK INK PEN

7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please mark the box below the percentage that most shows how much relief you have received.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No Relief										Complete Relief

9. Mark the box beside the number that describes how, during the past 24 hours, pain has interfered with your:
A. General Activity

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

B. Mood

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

C. Walking ability

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

D. Normal Work (includes both work outside the home and housework)

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

E. Relations with other people

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

F. Sleep

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

G. Enjoyment of life

<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
Does Not Interfere										Completely Interferes

Brief Fatigue Inventory

STUDY ID# _____

HOSPITAL # _____

Date: ____/____/____

Time: _____

Name _____

Last

First

Middle Initial

Throughout our lives, most of us have times when we feel very tired or fatigued. Have you felt unusually tired or fatigued in the last week? Yes ☐ No ☐

1. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your fatigue right NOW.

0	1	2	3	4	5	6	7	8	9	10
No										As bad as
Fatigue										you can imagine

2. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your USUAL level of fatigue during past 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No										As bad as
Fatigue										you can imagine

3. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your WORST level of fatigue during past 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No										As bad as
Fatigue										you can imagine

4. Circle the one number that describes how, during the past 24 hours, fatigue has interfered with your:

A. General activity

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely Interferes

B. Mood

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely Interferes

C. Walking ability

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely Interferes

D. Normal work (includes both work outside the home and daily chores)

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely Interferes

E. Relations with other people

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely Interferes

F. Enjoyment of life

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely Interferes

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Body Image Disturbance Questionnaire

Please answer the following questions about how you feel about your body				
1) Are you concerned about the appearance of some part(s) of your body which you consider especially unattractive?				
Not at all concerned	Somewhat concerned	Moderately concerned	Very concerned	Extremely concerned
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What are these concerns? What specifically bothers you about the appearance of these body parts?				
2) If you are at least somewhat concerned, do these concerns preoccupy you? That is, you think about them a lot and they're hard to stop thinking about?				
Not at all preoccupied	Somewhat preoccupied	Moderately preoccupied	Very preoccupied	Extremely preoccupied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What effect has your preoccupation with your appearance had on your life? _____				
3) Has the physical effect of your disease often caused you a lot of distress or torment? How much?				
Not at all distressed	Somewhat distressed	Moderately distressed	Very distressed	Extremely distressed
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) Has the physical effect of your disease caused you impairment in social, occupational or other important areas of functioning? How much?				
No limitation	Mild interference	Moderate, still manageable	Severe interference	Extremely incapacitating
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) Has the physical effect of your disease significantly interfered with your social life? How much?				
Never	Occasionally	Moderately often	Often	Very often
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) Has the physical effect of your disease significantly interfered with your schoolwork, your job, or your ability to function in your role? How much?				
Never	Occasionally	Moderately often	Often	Very often
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If so, how? _____				
7) Do you ever avoid things because of your physical effect of your disease? How often?				
Never	Occasionally	Moderately often	Often	Very often
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If so, what do you avoid? _____				

PROMIS Item Bank v1.0 – Emotional Distress – Depression – Short Form 6a

Depression – Short Form 6a**Please respond to each question or statement by marking one box per row.**

In the past 7 days...		Never	Rarely	Sometimes	Often	Always
¹	I felt worthless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
²	I felt helpless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
³	I felt depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
⁴	I felt hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
⁵	I felt like a failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
⁶	I felt unhappy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

LEVEL 2—Anxiety—Adult****PROMIS Emotional Distress—Anxiety—Short Form**Name: _____ Age: _____ Sex: ☐ Male ☐ Female Date: _____

If the measure is being completed by an informant, what is your relationship with the individual? _____

In a typical week, approximately how much time do you spend with the individual? _____ hours/week

Instructions to patient: On the DSM-5 Level 1 cross-cutting questionnaire that you just completed, you indicated that *during the past 2 weeks* you (individual receiving care) have been bothered by “feeling nervous, anxious, frightened, worried, or on edge”, “feeling panic or being frightened”, and/or “avoiding situations that make you anxious” at a mild or greater level of severity. The questions below ask about these feelings in more detail and especially how often you (individual receiving care) have been bothered by a list of symptoms during the past 7 days. Please respond to each item by marking (✓ or x) one box per row.

In the past SEVEN (7) DAYS....							Clinician Use
	Never	Rarely	Sometimes	Often	Always		Item Score
1. I felt fearful.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5		
2. I felt anxious.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5		
3. I felt worried.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5		
4. I found it hard to focus on anything other than my anxiety.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5		
5. I felt nervous.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5		
6. I felt uneasy.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5		
7. I felt tense.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5		
Total/Partial Raw Score:							
Prorated Total Raw Score:							
T-Score:							

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DISABILITIES OF THE ARM, SHOULDER AND HAND

THE
DASH**INSTRUCTIONS**

This questionnaire asks about your symptoms as well as your ability to perform certain activities.

Please answer *every question*, based on your condition in the last week, by circling the appropriate number.

If you did not have the opportunity to perform an activity in the past week, please make your *best estimate* on which response would be the most accurate.

It doesn't matter which hand or arm you use to perform the activity; please answer based on your ability regardless of how you perform the task.



DISABILITIES OF THE ARM, SHOULDER AND HAND

Please rate your ability to do the following activities in the last week by circling the number below the appropriate response.

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. Open a tight or new jar.	1	2	3	4	5
2. Write.	1	2	3	4	5
3. Turn a key.	1	2	3	4	5
4. Prepare a meal.	1	2	3	4	5
5. Push open a heavy door.	1	2	3	4	5
6. Place an object on a shelf above your head.	1	2	3	4	5
7. Do heavy household chores (e.g., wash walls, wash floors).	1	2	3	4	5
8. Garden or do yard work.	1	2	3	4	5
9. Make a bed.	1	2	3	4	5
10. Carry a shopping bag or briefcase.	1	2	3	4	5
11. Carry a heavy object (over 10 lbs).	1	2	3	4	5
12. Change a lightbulb overhead.	1	2	3	4	5
13. Wash or blow dry your hair.	1	2	3	4	5
14. Wash your back.	1	2	3	4	5
15. Put on a pullover sweater.	1	2	3	4	5
16. Use a knife to cut food.	1	2	3	4	5
17. Recreational activities which require little effort (e.g., cardplaying, knitting, etc.).	1	2	3	4	5
18. Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.).	1	2	3	4	5
19. Recreational activities in which you move your arm freely (e.g., playing frisbee, badminton, etc.).	1	2	3	4	5
20. Manage transportation needs (getting from one place to another).	1	2	3	4	5
21. Sexual activities.	1	2	3	4	5

DISABILITIES OF THE ARM, SHOULDER AND HAND

	NOT AT ALL	SLIGHTLY	MODERATELY	QUITE A BIT	EXTREMELY
22. During the past week, to what extent has your arm, shoulder or hand problem interfered with your normal social activities with family, friends, neighbours or groups? (circle number)	1	2	3	4	5

	NOT LIMITED AT ALL	SLIGHTLY LIMITED	MODERATELY LIMITED	VERY LIMITED	UNABLE
23. During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder or hand problem? (circle number)	1	2	3	4	5

Please rate the severity of the following symptoms in the last week. (circle number)

	NONE	MILD	MODERATE	SEVERE	EXTREME
24. Arm, shoulder or hand pain.	1	2	3	4	5
25. Arm, shoulder or hand pain when you performed any specific activity.	1	2	3	4	5
26. Tingling (pins and needles) in your arm, shoulder or hand.	1	2	3	4	5
27. Weakness in your arm, shoulder or hand.	1	2	3	4	5
28. Stiffness in your arm, shoulder or hand.	1	2	3	4	5

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	SO MUCH DIFFICULTY THAT I CAN'T SLEEP
29. During the past week, how much difficulty have you had sleeping because of the pain in your arm, shoulder or hand? (circle number)	1	2	3	4	5

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
30. I feel less capable, less confident or less useful because of my arm, shoulder or hand problem. (circle number)	1	2	3	4	5

DASH DISABILITY/SYMPTOM SCORE = $\frac{(\text{sum of } n \text{ responses})}{n} - 1 \times 25$, where n is equal to the number of completed responses.

A DASH score may not be calculated if there are greater than 3 missing items.

DISABILITIES OF THE ARM, SHOULDER AND HAND

WORK MODULE (OPTIONAL)

The following questions ask about the impact of your arm, shoulder or hand problem on your ability to work (including home-making if that is your main work role).

Please indicate what your job/work is: _____

☐ I do not work. (You may skip this section.)

Please circle the number that best describes your physical ability in the past week. Did you have any difficulty:

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. using your usual technique for your work?	1	2	3	4	5
2. doing your usual work because of arm, shoulder or hand pain?	1	2	3	4	5
3. doing your work as well as you would like?	1	2	3	4	5
4. spending your usual amount of time doing your work?	1	2	3	4	5

SPORTS/PERFORMING ARTS MODULE (OPTIONAL)

The following questions relate to the impact of your arm, shoulder or hand problem on playing your *musical instrument or sport or both*. If you play more than one sport or instrument (or play both), please answer with respect to that activity which is most important to you.

Please indicate the sport or instrument which is most important to you: _____

☐ I do not play a sport or an instrument. (You may skip this section.)

Please circle the number that best describes your physical ability in the past week. Did you have any difficulty:

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. using your usual technique for playing your instrument or sport?	1	2	3	4	5
2. playing your musical instrument or sport because of arm, shoulder or hand pain?	1	2	3	4	5
3. playing your musical instrument or sport as well as you would like?	1	2	3	4	5
4. spending your usual amount of time practising or playing your instrument or sport?	1	2	3	4	5

SCORING THE OPTIONAL MODULES: Add up assigned values for each response; divide by 4 (number of items); subtract 1; multiply by 25.

An optional module score may not be calculated if there are any missing items.



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Sexual Health Needs Assessment Questionnaire

How interested are you in receiving care to address sexual issues?	<ul style="list-style-type: none">• Very interested• Somewhat interested• Not at all interested
How likely is it that you would come to see one of our colleagues to have sexual matters addressed?	<ul style="list-style-type: none">• Very likely• Somewhat likely• Unlikely• Very unlikely
Have you recently sought advice or medical help for problems related to sexuality?	<ul style="list-style-type: none">• Yes• No
If you have sought help for problems related to sexuality, how satisfied were you with the care you received?	<ul style="list-style-type: none">• Very satisfied• Somewhat satisfied• Dissatisfied• Very dissatisfied
Would you be willing to be contacted if we develop a formal program to address sexual issues for women?	<ul style="list-style-type: none">• Yes• No

Sexual Health Needs Assessment Questionnaire

FICA Tool	
F – Faith, Belief, Meaning	<p>Religious/Religiosity – Pertains to one’s beliefs, behaviors, values, rules for conduct, and rituals associated with a specific religious tradition or denomination (O’Brien, 1999).</p> <p>Spirituality – Generally, an “individual’s attitude and beliefs related to transcendence (God) or to the nonmaterial forces of life and of nature...the dimension of a person that is concerned with ultimate ends and values” and meaning (O’Brien, 1982, p. 88; Taylor, 2006).</p>
<ul style="list-style-type: none"> Do you consider yourself spiritual or religious? 	
<ul style="list-style-type: none"> Do you have spiritual beliefs that help you cope with stress? 	
<ul style="list-style-type: none"> What gives your life meaning? 	
I – Importance and Influence	
<ul style="list-style-type: none"> What importance does your faith or belief have in your life? 	
<ul style="list-style-type: none"> On a scale of 0 (not important) to 5 (very important), how would you rate the importance of faith/belief in your life? 	
<ul style="list-style-type: none"> Have your beliefs influenced you in how you handle stress? 	
<ul style="list-style-type: none"> What role do your beliefs play in your health care decision making? 	
C – Community	
<ul style="list-style-type: none"> Are you a part of a spiritual or religious community? 	
<ul style="list-style-type: none"> Is this of support to you and how? 	
<ul style="list-style-type: none"> Is there a group of people you really love or who are important to you? 	
A – Address in Care	<p>We have talked a lot about your spirituality and/or religious beliefs and how they may or may not be of help to you during your illness. How can your health care providers best support your spirituality?</p>
<ul style="list-style-type: none"> How would you like your health care provider to use this information about your spirituality as they care for you? 	

Work Productivity and Activity Impairment Questionnaire:
Specific Health Problem V2.0 (WPAI:SH~~HP~~)

The following questions ask about the effect of your PROBLEM on your ability to work and perform regular activities. Please fill in the blanks or circle a number, as indicated.

1. Are you currently employed (working for pay)? _____ NO ____ YES
If NO, check "NO" and skip to question 6.

The next questions are about the **past seven days**, not including today. |

2. During the past seven days, how many hours did you miss from work because of problems associated with your PROBLEM? Include hours you missed on sick days, times you went in late, left early, etc., because of your PROBLEM. Do not include time you missed to participate in this study.

_____ HOURS

3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?

_____ HOURS

4. During the past seven days, how many hours did you actually work?

_____ HOURS (If "0", skip to question 6.)

5. During the past seven days, how much did your **PROBLEM** affect your productivity while you were working?

*Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If **PROBLEM** affected your work only a little, choose a low number. Choose a high number if **PROBLEM** affected your work a great deal.*

Consider only how much **PROBLEM** affected productivity while you were working.

PROBLEM had no effect on my work	0	1	2	3	4	5	6	7	8	9	10	PROBLEM completely prevented me from working
--	---	---	---	---	---	---	---	---	---	---	----	---

CIRCLE A NUMBER

6. During the past seven days, how much did your **PROBLEM** affect your ability to do your regular daily activities, other than work at a job?

*By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If **PROBLEM** affected your activities only a little, choose a low number. Choose a high number if **PROBLEM** affected your activities a great deal.*

Consider only how much **PROBLEM** affected your ability to do your regular daily activities, other than work at a job.

PROBLEM had no effect on my daily activities	0	1	2	3	4	5	6	7	8	9	10	PROBLEM completely prevented me from doing my daily activities
--	---	---	---	---	---	---	---	---	---	---	----	--

CIRCLE A NUMBER

WPAKSHB V2.0 (US English)

Reilly MC, Zupack AS, Dukes E: The validity and reproducibility of a work productivity and activity impairment measure. *Pharmacoeconomics*. 1993; 4(5):353-365.

Quality of Life Scale/CANCER PATIENT/CANCER SURVIVOR

Directions: We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life **at this time**.

Please circle the number from 0 - 10 that best describe your experiences:

Physical Well Being

To what extent are the following a problem for you:

1. **Fatigue**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

2. **Appetite changes**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

3. **Aches or pain**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

4. **Sleep changes**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

5. **Constipation**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

6. **Nausea**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

7. **Menstrual changes or fertility**

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

8. **Rate your overall physical health**

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

Psychological Well Being Items

9. How difficult is it for you to **cope** today as a result of your disease and treatment?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very difficult**
difficult

10. How good is your **quality of life**?

extremely 0 1 2 3 4 5 6 7 8 9 10 **excellent**
poor

11. How much **happiness** do you feel?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

12. Do you feel like you are **in control** of things in your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

13. How **satisfying** is your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

14. How is your present ability to **concentrate** or to **remember** things?

extremely 0 1 2 3 4 5 6 7 8 9 10 **excellent**
poor

15. How **useful** do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

16. Has your illness or treatment caused changes in your **appearance**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

17. Has your illness or treatment caused changes in your **self concept** (the way you see yourself)?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

How distressing were the following aspects of your illness and treatment?

18. Initial diagnosis

not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing
distressing

19. Cancer treatments (i.e. chemotherapy, radiation, or surgery)

not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing
distressing

20. Time since my treatment was completed

not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing
distressing

21. How much anxiety do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

22. How much depression do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

To what extent are you fearful of:

23. Future diagnostic tests

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

24. A second cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

25. Recurrence of your cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

26. Spreading (metastasis) of your cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

Social Concerns

27. How distressing has illness been for your **family**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

28. Is the amount of **support** you receive from others sufficient to meet your needs?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

29. Is your continuing health care interfering with your **personal relationships**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

30. Is your **sexuality** impacted by your illness?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

31. To what degree has your illness and treatment interfered with your **employment**?

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

32. To what degree has your illness and treatment interfered with your **activities at home**?

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

33. How much **isolation** do you feel is caused by your illness or treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

34. How much **financial burden** have you incurred as a result of your illness and treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

Spiritual Well Being

35. How important to you is your participation in **religious activities** such as praying, going to church?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very important**
important

36. How important to you are other **spiritual activities** such as meditation?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very important**
important

37. How much has your **spiritual life** changed as a result of cancer diagnosis?

less 0 1 2 3 4 5 6 7 8 9 10 **more important**
important

38. How much **uncertainty** do you feel about your future?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very uncertain**
uncertain

39. To what extent has your illness made **positive changes** in your life?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

40. Do you sense a **purpose/mission** for your life or a reason for being alive?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

41. How **hopeful** do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 **very hopeful**
hopeful